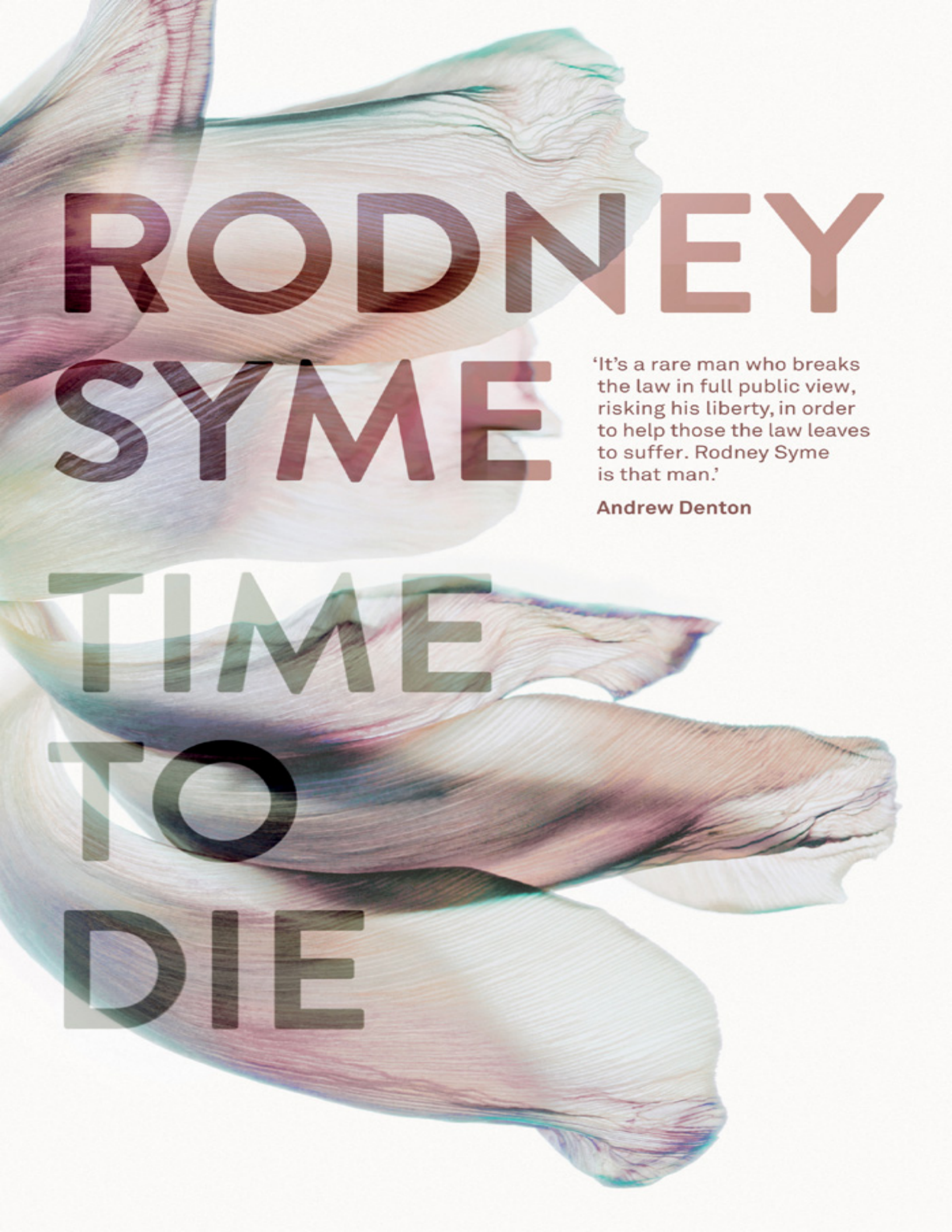

RODNEY SYME

TIME TO DIE

'It's a rare man who breaks the law in full public view, risking his liberty, in order to help those the law leaves to suffer. Rodney Syme is that man.'

Andrew Denton

RODNEY SYME

TIME TO DIE

MELBOURNE UNIVERSITY PRESS

MELBOURNE UNIVERSITY PRESS
An imprint of Melbourne University Publishing Limited
Level 1, 715 Swanston Street, Carlton, Victoria 3053, Australia
mup-info@unimelb.edu.au
www.mup.com.au

First published 2016
Text © Rodney Syme, 2016
Design and typography © Melbourne University Publishing Limited, 2016

This book is copyright. Apart from any use permitted under the *Copyright Act 1968* and subsequent amendments, no part may be reproduced, stored in a retrieval system or transmitted by any means or process whatsoever without the prior written permission of the publishers.

Every attempt has been made to locate the copyright holders for material quoted in this book. Any person or organisation that may have been overlooked or misattributed may contact the publisher.

Cover design by Pfisterer + Freeman
Typeset by TypeSkill
Printed in Australia by McPherson's Printing Group

National Library of Australia Cataloguing-in-Publication entry

Syme, Rodney, author.

Time to die/Rodney Syme.

9780522870930 (paperback)
9780522870947 (ebook)

Includes index.

Suffering.
Death.
Euthanasia.
Assisted suicide.

CONTENTS

1 Is this the best we can do?
2 A good death and the lessons learned
3 Counselling
4 Advanced incurable illness
5 Suffering
6 Palliative care
7 Dignity, vulnerability and burden
8 The medicalisation of dying
9 Dying well, dying badly
10 The momentum for change
11 Bill and Mary
12 The future

Postscript
With respect and gratitude
Bibliography
Index

1

IS THIS THE BEST WE CAN DO?

Rudi Dobron was slowly dehydrating and starving to death, like someone with advanced dementia, but he was completely competent and aware of the fact, and fully conscious of its effects. He had initiated the process.

Rudi's problem was not a lack of awareness of the significance of food and drink, as can occur with dementia, or a lack of hunger, but an inability to swallow. He had laryngeal cancer, which ultimately led to the removal of his larynx; an inability to speak; and, finally, the inability to swallow even his own saliva. He became determined to die by refusing food and fluids, hoping it would happen reasonably quickly and peacefully. However, he died forty-seven days later, having been in the hands of a Catholic palliative care unit.

Rudi was sixty-three when, in 2004, he first developed the symptoms of his vocal cord cancer, which was treated conservatively (conserving his ability to speak) by six weeks of radiotherapy. He was pronounced cured, but required

some follow-up laser surgery, and, finally, when his cancer recurred three years after its initial discovery, he was told that removal of his larynx was the only option.

Many people might think that after two failed procedures, both termed ‘successful’ at the time, the outlook of further surgery was not bright, but Rudi was not a quitter—the life he shared with a devoted partner was precious to him—he wanted to live and he was prepared to take the chance, even though he would be unable to speak normally. So he underwent a complete removal of his larynx, and creation of a permanent tracheostomy (an opening of the breathing passage in the neck). He would have to learn to swallow air into his stomach, and attempt to make understandable sounds as he forced this air back up his oesophagus into his mouth.

But the cancer had affected Rudi’s oesophagus and he required a further major operation—removing the oesophagus, with a length of small intestine being used to bridge the gap between his pharynx and his stomach. These operations were ‘successful’ in that he survived them both, but he could no longer speak, and from early on had significant difficulty swallowing, which grew steadily worse.

Four months later, a lump was found growing in his neck, which proved to be a recurrence of the cancer in his lymph nodes. The lump was attached to his carotid artery and irremovable. Chemotherapy was the only option, although it, at best, might buy him some time.

Once again, Rudi’s desire to live kicked in, and he accepted the proposal of six cycles of in-patient chemotherapy, with its probable side effects. As would most of us, he still hoped that this further treatment would extend both his quality and quantity of life. He bravely entered a clinical trial to try to determine if this was likely. However, with Rudi suffering from mouth ulcers, constipation, diarrhoea, loss of appetite and pneumonia, his oncologist decided to cease treatment, as it was having no benefit.

In the ten months since the operation to remove his oesophagus, he had gone rapidly downhill. By early October 2008, while any pain was controlled by the oral liquid morphine used in home palliative care, he had extreme difficulty even swallowing liquids, and had occasional shortness of breath. He had sustained significant weight loss and was burdened by a corresponding loss of energy. He was beginning to starve to death.

While listing Rudi's physical distresses, it is easy to overlook his loss of speech. I was reminded of this when visiting a woman with motor neurone disease (MND) and her husband. She had the bulbar type of the disease, which paralyses the ability to swallow and speak, and later to breathe, while usually leaving the mind quite intact. This highly intelligent and much-travelled woman sat on a couch, her daughter feeding her via a percutaneous endoscopic gastrostomy (PEG) (a tube that goes through the abdomen to the stomach), using a large syringe. Her husband sat and chatted with me about many things with which she was familiar, and about which she could have made an interesting contribution. But she lacked the ability to enter the conversation quickly, with humour or gravity, supplying knowledge or asking a question—for this, timing is all important. Sure, she could interrupt the talk and write a sentence on her board; but she could only be a small part of the conversation, not really in it. As I watched her, I slowly realised how frustrated she was, and when we were alone she confirmed her distress to me.

Christopher Hitchens, the renowned journalist and critic, developed cancer of the vocal cords, and died of it in late 2011. In one of his last published pieces (*Vanity Fair,* June 2011), he pondered the loss of speech, and his imminent loss of the ability to write, due to nerve damage from his medication. He wrote, 'to lose this ability [communication] is to be deprived of an entire range of faculty: it is assuredly to die more than a little'. Further, 'my chief consolation in

this year of living dyingly has been the presence of friends. I can’t eat or drink for pleasure anymore, so when they offer to come it’s only for the blessed chance to talk’. Hitchens was writing from the perspective of a foremost exponent of the written and spoken word, but his final longing was for the joy of communication with friends.

It’s easy to forget the oppression of the soul that accompanies loss of the ability to communicate; it is a kind of suffering that does not register in the medical lexicon, but to a patient it is a fundamental loss. It is not likely to be considered something that needs palliation; indeed, and more to the point, it is almost impossible to palliate effectively.

It is all too easy to lose sight of the fact that Rudi had been unable to taste any food or drink for some time, and to take part in a meal with others. Let’s reflect for a moment on the social—human—significance of communal eating and drinking. It is an essential part of being, something we share with others from when our life begins. Author Jon Reiner, in his memoir *The Man Who Couldn’t Eat*, describes the ‘loss of sense of self’ and the ‘loss of social interaction’ involved in the loss of the ability to eat.

These two phenomena, the loss of speech and the loss of eating, highlight perfectly the nature of existential suffering. Neither causes physical pain, but cause greater psychic pain. Physical pain can be alleviated, but these losses cannot be altered and therein lies the profound nature of existential suffering. It goes to the essence of who we are, of why we are here, of what we can do and achieve. If you have a devout belief in an afterlife, you may perhaps be able to overcome such losses, but many people do not have such a belief and cannot make such a quantum leap to accept these losses in their dying days. Unfortunately, palliative care in day-to-day practice seems to have little understanding of existential and psychological suffering.

By this time, Rudi realised that there was no longer any hope—either of a significant further survival time, or of even minimal improvement in his already negligible quality of life. He felt that he was now a burden to his beloved partner, whose blood pressure had skyrocketed with the intense stress of coping with his illness. She did not complain, and wanted to care for him, but it was obvious to Rudi that she was having trouble coping, and imposing further demands on his partner was the last thing he wanted. His response was altruistic, not selfish; Rudi was ready to die. He sought my advice about managing the end of his life.

There was no longer a future, a purpose, a hope of better times. There would only be a progressive deterioration of his already awful circumstances, with intense and increasing suffering for himself and his partner.

Just as Rudi had been courageous about his treatment, he decided to face courageously his time to die and control it. He pondered how he could orally take medication to end his life with dignity and confidence, but his extreme swallowing difficulty left him doubtful that he could carry this out. His only other option was to stop eating and drinking. With good palliative care for his mouth and sufficient sedation, he could expect to die reasonably quickly (in about five to seven days) and with minimal physical suffering. (Palliative care journals frequently note the exquisite mouth care and impeccable symptom relief provided to patients who are no longer being given oral fluids, and the reassurance that there is no suffering due to thirst.)

Rudi already had home palliative care, and the visiting nurse had asked him if he was scared of death. He replied that he was not scared of death but of the way in which he would die. She reassured him by saying that in hospice he would be given ‘a few shots and out you go’—he thought that didn’t sound too bad. So, when it was suggested that

he enter in-patient palliative care for ‘respite’, for both him and his partner, he readily accepted.

In preparation for his end of life, Rudi had appointed his partner his medical enduring power of attorney (MEPA)—someone with legal power to make medical decisions if he was unable to do so himself and as his supportive advocate. He also prepared an advance directive, setting out his wishes for no further life-prolonging treatment, and for the provision of maximum relief of pain and suffering. He provided copies of these documents to in-patient palliative care. These were not found in his file after his death.

Under Victorian law (the Medical Treatment Act 1988), Rudi had a legal right to refuse any medical treatment, such as tube feeding or intravenous or subcutaneous infusions, and, as a dying patient, to receive maximum relief of pain and suffering. The law is consistent that any competent person has a right to refuse to eat and drink, and cannot be force-fed. Justice Kourakis of the South Australian Supreme Court confirmed this (*H Ltd v J* [2010] SASC 176), stating that there was no common law duty to provide nourishment to rational, informed persons who voluntarily refuse oral food and fluids. Such refusal is not considered suicide. Further, Chief Justice Martin of the Supreme Court of Western Australia (*Brightwater Care Group v Rossiter* [2009] WASC 229) stated that treating doctors’ obligations are no different in this situation from the obligations that attend the treatment of any other patient who may be approaching death.

Decisions by senior justices in state Supreme Courts usually have a powerful effect in other state jurisdictions. Rudi should have been able to have confidence in his decision to refuse all food and fluid, and expect compassionate care. As it turned out, he was thwarted in both of these crucial matters.

Rudi entered the Caritas Christi palliative care unit on 15 October 2008. He died there on 1 December 2008, forty-

seven days later. Throughout that time he insisted that he did not want to eat or drink, and requested that he be kept comfortable. This was a rational and persistent decision, supported by his partner, who was his MEPA, yet was not supported—and was, in many ways, obstructed—during palliative care.

The details of Rudi's final seven weeks of life in palliative care are contained in his medical record, which was obtained through freedom of information. His admission note stated that he 'is tolerating oral fluids' and staff were advised to 'encourage oral fluids as tolerated'. A nurse noted, on the same day, that 'he takes fluids slowly through a straw' and that 'fluid can go up his nose'. Four days later, he was 'not able to eat or drink—goes up his nose'. Meanwhile, despite his advance directive specifically rejecting tube feeding, his palliative care physician discussed introducing a PEG. This was initially fair enough, for Rudi might have changed his mind since completing the directive. However, despite his emphatic rejection of such a procedure, the clinical notes stated, 'they would like some time to think about a PEG'. Nine days later, the record stated he is 'presently unable to eat or drink', and two days later that he 'flatly refused oral fluids'. Three days later, the specialist care physician stated there was 'complete obstruction', and, despite his patient's previous instructions, 'spoke about subcutaneous fluids—not for now'. He clearly refused to accept Rudi's persistent rational decision, and made no attempt to provide the palliation requested. One day later, 'daggy mouth' and a white-coated tongue, evidence of poor oral care, were recorded. It was not until 17 November, more than a month since Rudi's admission, when he first requested sedation, that twenty-four-hour sedation was commenced in minute doses.

There is plenty of corroborative evidence of Rudi's wishes. On 21 October, the pastoral care worker stated he had 'no wish to engage', while, three days later, a nurse found he

was ‘tired and depressed’, and two days after that, that he was ‘happy to be dehydrated because then he will die earlier’. Three other entries, on 26 October, stated he was ‘happy to communicate feelings, now wanting sedation’, that ‘he said he has reached the stage when he wants to be sedated’, and that ‘he just wants to be unaware’. Remarkably, no sedation was given. On 27 October, the record showed ‘Rudi frustrated’. He had discussed nighttime sedation, which was available. Again, no nighttime sedation is recorded being given. Later that day, pastoral care visited and observed that he ‘expressed a desire to die, his feeling of being a burden, of having no quality of life’. On 30 October, the entry said that he ‘does not want life-prolonging measures’.

The above observations leave no doubt that Rudi was ready to die, that he wanted to stop eating and drinking and receive sedation to achieve this end, but he was given no support. His frustration and understandable depression at his circumstances are evident. His psychological suffering is clear in the entry of 30 October that ‘he has a scared look in his eyes today which I haven’t seen before’. Could it have been because ‘he feels he is choking’? This note was repeated on 31 October, together with one that he was suffering from ‘discomfort and shortness of breath’.

Eighteen days after Rudi’s admission (2 November), a new phase commenced—hallucinations, which are a clear sign of severe mental distress. He was encouraged to talk about his hallucinations and prescribed the anti-psychotic and sedative drug haloperidol. On 8 November, the entry noted ‘hallucinations, confused, illusions, disorientation’. On 10 November, an extraordinary entry says ‘Patient feeling well—hallucinations’. By 12 November, ‘hallucinations becoming more pervasive’ and a day later it was recorded he was hallucinating ‘insects’. Four days later the record stated that he had ‘generalized pain and restlessness and is not able to sleep’. Worse was to follow. Notes for the next

day stated that he was agitated, experiencing ‘anguish’ and was ‘fed up’, and was having difficulty sleeping at night. Twenty-four-hour sedation commenced, nearly a month after he first requested it.

As well, for a large part of his seven-week stay in palliative care, Rudi suffered from incontinence. For the first eleven days he was constipated, and then lost control of his bowels and had to wear a nappy. There are ten separate references to incontinence of faeces, and he developed a pressure sore over his sacrum. On 10 November, he became incontinent of urine and on 18 November he saturated his bed. This continued intermittently until 30 November, when the entry states, astoundingly, ‘peaceful morning—bowels incontinent x 2’. The only reason Rudi was peaceful was that he was deeply comatose from the medication he was receiving; it was a small mercy that he was unaware of this indignity. He died the next day.

You would imagine that at least Rudi would have been free of pain, as would be expected of palliative care. From 23 October, he was prescribed opioids in small amounts by syringe driver: initially, 20 milligrams of morphine over twenty-four hours (post-operative pain relief can require more than 60 milligrams over the same amount of time). Nine days later this was increased to 25 milligrams, and then to 35 milligrams three days later. There it remained till 16 November, when it was increased to 45 milligrams, and then twenty-four-hour sedation started, with minimal doses of midazolam (10 milligrams over twenty-four hours), increasing to 25 milligrams on 30 November (a routine sedative dose to enable light sleep is 5 milligrams).

Rudi did not complain of pain from the enlarging cancer mass in his neck, but complained persistently of headache. There were fourteen records of nocturnal headaches waking him between 24 October and 20 November, but no evidence of any effective action to relieve this. Perhaps a headache is not considered real pain in palliative care—that an ache is

rather minimal. For my part, the occasional headaches I have suffered have been the worst pain I have experienced. I would not regard Rudi as having been free of pain for much of his care. The doses of analgesia and sedation prescribed were minimal in strength, particularly considering the ethical imperative that patients should not die with unrelieved suffering.

Rudi made mention of his feeling of choking at times. Early in his admission to palliative care, his doctors made provision for a large bolus injection of morphine and sedative if he suffered a catastrophe (namely, choking due to airway obstruction, or acute carotid haemorrhage), but did not seem to regard his ongoing starvation, incontinence, severe headache, and emotional and existential trauma, as a catastrophe.

From the time Rudi's twenty-four-hour sedation commenced on 17 November, there were few entries regarding complaints except that he was drowsy and weak (18 and 20 November), and over the following five days he remained 'responsive'. Bear in mind that Rudi could not talk, and at this stage could not use his writing board—he was helpless. One day after the sedation began, he was drowsy; and two days later, unresponsive, as he remained until he died six days later.

Rudi had been the beneficiary of continuous sedation (with continuous pain relief) because his suffering was now of the type that palliative care practitioners considered to be refractory—the term they use to describe symptoms they can no longer relieve. Such refractory suffering requires continuous sedation for relief, but the level of sedation initially provided was such that Rudi remained aware of his circumstances for a further seven days before becoming comatose. No one could say that this was deep sedation, or that the amount of drugs had hastened his death; no sir, the palliative record was clean on that score. It had neither prolonged his life nor hastened his death, as the palliative

care mantra goes. But, equally, neither could you say that Rudi had maximal relief of his pain and suffering, as the Medical Treatment Act 1988 allows.

In my view, Rudi experienced unremitting suffering from the time he entered palliative care. That was also the view of his partner, who spent a great deal of time with him and thought Rudi's death was 'horrible'. She had seen herself as Rudi's advocate, as he could not speak, although he was initially quite lucid and could write his wishes and complaints. She said later, in an interview with *The Age* journalist Julia Medew, 'the medics well knew where we stood and that was not to allow to happen what did'. They were given Rudi's advance directive, but, strangely, it could not be found in his medical record after he died. Despite both Rudi and his partner asking for him to receive sedation and increased pain relief, they were told that 'sedation would lose its efficacy if introduced too early', and that increasing morphine can be 'counter-productive as the body adjusts to doses'. The first quote is nonsense, and the second is only partially true—increasing doses does lead to tolerance, but relief is still provided by larger doses. There was no reason, in the circumstances, not to increase his dose to one that actually worked.

Before Rudi became confused and began to hallucinate, he wrote a note that was intended for the media, but he had second thoughts about making it public, as he did not want to cause harm to Caritas. He asked his partner to put it in the rubbish bin, but she kept it, and showed it to his doctor shortly after he had written it:

> I am dying of cancer of the throat. I can no longer control my bowels nor eat or drink. If I was a pet I would have had a peaceful injection days ago. But I am human and so I will have to go through the barbaric religious ritual of dying without dignity from dehydration over weeks. Incidentally I am an organ donor. By the end of this type of death my kidneys and other now healthy organs will also be dead. Can't eat or drink anything. Been still losing fluid for 5 days now. Getting increased dosage of morphine and other stuff.

His partner reflected while talking to to Julia Medew:

> the above sounds like a note from an explorer who realizes he is lost, not an intelligent thinking person, not in the centre of a desert, but in Kew with all amenities at hand. His body was so strong it beat records for subsisting on nothing for seven weeks. It astounded the medicos, but he was not in the hospice to break records but to be shown enough empathy to assist him in reaching a peaceful end when he could no longer talk or write or even reach for the bell for the nurse if required.

Let's not forget the effect this disaster is having on Rudi's partner and family. On more than one occasion, she was told on visiting that he was 'peaceful', only to find him quite agitated—trying to get out of bed, or removing all his bedclothes or sometimes his clothes—one day, all he had left on was the nappy! It was only then that he was given minimal twenty-four-hour sedation. This experience added to the guilt his partner felt—she had the responsibility of being his advocate, frequently making representations on his behalf and getting no response, and watching him die miserably. She told Julia Medew:

> I would come home from visiting him, cook some food, and then think why should I have the right to eat when he could not. The last day before he died I came home and thought I cannot keep on going in [he had been totally unresponsive for a week].

Dying with dignity? Give me a break. And all this occurred in one of Victoria's supposedly best hospices.

Rudi was ready to die when he entered palliative care. His 'natural' death occurred seven weeks later. Could anyone doubt that in this time he underwent intolerable suffering, which would have been avoided by an earlier death? Does this not suggest that his palliative care, dedicated as it was to the relief of suffering, was seriously inadequate?

Rudi's palliative care was flawed, and failed, because of palliative futility. He was suffering from circumstances that the very best of care could not alter; that is, further attempts

at palliation were bound to be futile, unless sufficient sedation and pain relief made him unaware of his suffering. Let us look critically at these circumstances.

Rudi's primary problem was his inability to swallow; it was practically a complete obstruction, although some fluid must have been absorbed for him to have survived so long. He did take fluids to keep his mouth moist, and spat them out, because they went up into his nose if he tried to swallow. He could no longer enjoy the taste of food, and had lost his appetite. Lack of food led inevitably to starvation, and gradual dehydration. Of course, this led to progressive loss of weight, and weakness. Are any of these problems alterable by palliation? No, unless a PEG is placed in the body, and Rudi wisely rejected this (as was his right); it would simply have prolonged his suffering, because it would not have affected his other problems.

Loss of control of your bodily functions is one of the most potent causes of loss of dignity known to humankind, and Rudi suffered from both urinary and faecal incontinence throughout his forty-seven days in hospice. Nurses, of course, are used to dealing with this, and an indication of their insensitivity due to familiarity was the entry the day before Rudi died: 'peaceful morning—bowels incontinent x 2'. Was his loss of dignity diminished by his deep unconsciousness? Was this incontinence alterable? Possibly, but only by invasive treatments, perhaps disproportionate to the situation, which highlights a problem with much palliative care—each intervention to attempt palliation of a symptom risks inducing further complications. A recent article by Debra Rowett and David Currow in *Australian Prescriber* (December 2014) highlights that, after more than fifty years of specialist palliative care, much of the pharmaceutical care remains experimental in nature in regard to any individual patient.

Rudi suffered from constipation prior to his faecal incontinence. The constipation was probably due to the

morphine, and the incontinence was probably a consequence of the constipation, an overflow phenomenon from his impacted rectum. One thing leads to another, which is one reason there is commonly an escalation (sometimes a crescendo) of suffering at the end of life, which makes for enormous difficulty with effective palliation. So, palliative care is not as effective as many, in palliative care, government and the Catholic Church in particular, would have us believe.

Relief of pain is palliative care's trump card, so it is hard to understand why Rudi's persistent headaches went unaddressed, even though they were reported. This failure of relief was appalling.

If there is one thing palliative care can do for dying patients, it is to keep them free of pain. Yet, I have observed on the few occasions I have been closely aware of palliative care practice that the doses of analgesics used are often quite small, and are increased with reluctance, and only in response to lack of control of the pain, rather than anticipating increasing pain and preventing it.

So much for Rudi's physical suffering. What about his psychological and existential suffering? These central aspects of suffering, equally significant to dying people as is physical suffering, have been largely ignored by palliative care until ten years ago, when evidence emerged from Oregon that they were central to end-of-life suffering, and the principal reasons for requests for earlier deaths.

Rudi showed clear evidence of psychological suffering, with the references to his anxiety, frustration, fear, confusion, disorientation, and, ultimately, hallucinations. The response? Minimal doses of haloperidol (an antipsychotic and sedative drug), commenced after the hallucinations first occurred but were ineffective over the next two weeks, until twenty-four-hour sedation with midazolam began. To write a pres cription is not palliation—elimination of the symptom is palliation. Rudi sought

sedation of his distress from the day he entered hospice—the record makes frequent reference to this—but effective sedation was not provided until five weeks later, two weeks before he died. Why?

Then there is the question of existential suffering. People who do not understand its meaning have criticised me for using this term, but there is no better word to explain one of the most significant aspects of suffering. Think about it—it relates to your existence, those things that give your life pleasure, or, perhaps, make it endurable. Consider Rudi's existence. He had entered hospice willingly, believing his wishes would be respected, and that, with appropriate medication, he would die quickly and painlessly. The reality was that he found himself incarcerated in a hostile environment, where the people treating him were not listening to him, were ignoring and frustrating his wishes, and prolonging his suffering. He had lost control over his life, which had lost all purpose.

Rudi could not talk and could not eat; fundamental human needs, but seemingly of no account to his carers. He was aware of the burden, the stress, that his prolonged dying was causing his partner, and he wanted no part in increasing that burden. He had become completely dependent on other people who *talked to him, not with him.* This in itself is a loss of dignity, to have all the power lying in the hands of his 'carers'. They had taken away any sense of having control over his life—he was trapped in a hostile place, in the hands of powerful people who did not hear him. He was unable to go home due to his total dependence. The only control he had was to decide to stop eating and drinking, with appropriate nursing and medical care to ensure that he did not suffer, but his 'carers' refused to engage with him. Why?

Medew interviewed Rudi's palliative care physician some months after his death. He said that Rudi had enough medication to control his pain, and that when Rudi asked

about sedation, it was discussed and he decided against it or agreed to particular levels. The palliative care physician and a colleague were quite convinced that Rudi had been given good palliative care and they had nothing to apologise for. ‘I think we did a very good job’; his care was ‘overwhelmingly around comfort and him feeling quite well’.

How could they have got it so wrong? Rudi’s letter and his partner’s distress indicate they were not listening, and completely misunderstood his needs, values and wishes.

To my mind, Rudi severely suffered in all three loosely connected domains of suffering—physical, psychological and existential—and they were not palliated, because they could not be effectively palliated. He was in a place of palliative futility. Does that mean his suffering should have been ignored? Surely his clearly expressed ‘time to die’ should have been respected?

Rudi entered palliative care ready to die; specifically, he had reached his time to die. Yet, he then endured another forty-seven days of terrible suffering and denial of his clearly expressed wishes, while in palliative care. Perhaps palliative control is a more accurate term.

My previous book, *A Good Death,* was predominantly concerned with people dying, as Rudi was, of cancer—in short, people with terminal illness, who had weeks or months to live. It was mainly about my involvement in their deaths. My concerns have expanded to consider the reality of palliative care, and the suffering of those people who are not actually dying—a group I call the advanced incurably ill. It is time we faced up to what is the effective care these people require from us as a caring society. Their suffering is fundamentally no different from that of a dying person, and their requests for relief of their suffering must be respected, even if it means providing assistance for them to control the end of their lives.

2

A GOOD DEATH AND THE LESSONS LEARNED

In 2008, Melbourne University Press published my book *A Good Death.* This came about in a vicarious way. In 1974, I was both in private practice and a consultant in urology at the Austin Hospital. In 1972, I had removed Betty's kidney cancer, but it spread to her spine, causing unrelievable neuropathic (nerve) pain. This experience made me think about an aspect of medicine I had not previously considered—the possibility, ultimately the necessity, of assisted dying. I read a wide range of the medical and bioethical literature on this subject. From about 1987, I began to comment publicly on the matter, which led, particularly after 1992, to a steady increase in people with non-urological diseases seeking my advice.

In 1993, Alice, who had multiple sclerosis (MS), approached me; in 1993–94, Anna, who had ovarian cancer, rang me; and in 1995, Margaret, who had MND, got in touch.

They all sent me very powerful letters, in answer to my request that they express their feelings, which I thought could help to clarify their thinking, and assist me in my response. Anna's formed the backbone of a persuasive article in *The Age* by freelance London journalist Nick Davies, in support of the Northern Territory's Rights of the Terminally Ill Act 1995. It featured the Melbourne Seven, a group of seven Melbourne doctors who publicly acknowledged having assisted patients to die, theoretically in breach of the law.

By the early 2000s, I had counselled hundreds of people, and assisted a number to die. I realised that I probably had experience in this area unique in Australia, and that it would be a loss not to document it. So, one weekend on Phillip Island, I audio-recorded Margaret's story. This, coupled with the realisation the authorities did not seem to have an intent to prosecute me, was the genesis of *A Good Death*.

It starts with my epiphany in 1974, and ends in 2005, with my involvement in the death of Steve Guest. He was wasting away to skin and bone from oesophageal cancer, and publicly castigated those who denied him assistance to bring his suffering to an end. I provided him with medication that gave him control over the end of his life.

That 30-year experience involved a steep learning curve, as each encounter broke new ground, and taught me something new. Each human death has its own special qualities and level of unpredictability, because we are all individuals with different values, beliefs and life experiences, and, especially, different circumstances as we approach death. I believe that the lessons I learned from the stories in *A Good Death* are worth repeating because they are now relevant to a wider group of people.

Of Betty, who suffered from kidney cancer that had spread to her spine, with consequent spinal collapse and dreadful neuropathic pain, I wrote, 'As I approached the stairs leading to her room, I heard her screams of anguish as

the nurses tried to place her on a bed-pan'. This level of pain could only be relieved by anaesthesia, by terminal sedation (not developed by palliative care until 1988) or by death. This was my first fundamental lesson—*that some suffering will only end with death*. Betty's pain could have been minimised by repeated large doses of morphine, but the nurses were frightened to administer them. I should have taken the lead and given them myself; this was a mistake I would not make again.

In 1975, Ken was in hospital, in the last stages of heart failure, when his family asked me to visit him. I knew him very well (he was my wife's uncle), and had discussed his end-of-life views with him many times. It was another instance where the nurses were frightened to administer the dose of morphine that had been ordered. I asked them to draw up the injection, and administered it myself, intravenously. Minutes earlier, he had gasped, between strangled breaths, 'Help me.' As his breathing eased, his last words were 'Thank you.' He died two hours later without regaining consciousness. I was not aware then of the statement that Doctor Louise Gibbs and colleagues (*British Medical Journal*, 1998) had made that such persons could have 'symptoms as severe as those with cancer managed … by palliative care services'. Ken taught me that it could be *a necessity to hasten death in order to relieve intolerable and unrelievable suffering*.

In 1976, Len had incurable bladder cancer (radiotherapy having failed) with intractable urinary frequency and urgency, painful urination, incontinence, bleeding and intermittent blockage by clots. He was the epitome of the surgeon's long-held aphorism 'Please, God, do not take me through my bladder.' Facing another futile admission to hospital, he asked me, 'Isn't there anything else you can do?' Non-specific though this question was, I knew exactly what it meant. Naively, I prescribed him the maximum prescribable quantity of sleeping tablets, which he took, but

he did not die until a week later, of complications rather than from the medication, although he remained unconscious. Len taught me the *need for careful dialogue and considered decision-making*. When, a month later, the police phoned me on behalf of the coroner, with a warning to be more careful with my prescribing, I realised the *potential risk of providing such assistance*.

Nearly twenty years later, in 1993, Alice, who was suffering from MS, and having been thwarted in a suicide attempt, wrote seeking my help. She was not dying, but, almost totally paralysed and without bladder control, had no quality of life, felt she was a profound burden to her ageing husband and her daughter, and was close to incarceration in an institution. Overcoming my fear of possible criminal prosecution, I visited her, and tried to find a solution that would take me off the hook by avoiding any direct involvement in her death, but to no avail. Her subsequent letter stated, 'I am literally trapped in a situation, where my life would be unbearable if my absolutely total disabilities to which I am now very close, were to disable my right hand and my mind to a no hope of rescue situation for the rest of my intolerable life'. This shamed me into finding a way for her to take control of her death. This way was, however, far from ideal, because I still had inadequate knowledge of the appropriate medication. Alice taught me that *intolerable and unrelievable suffering was not confined to the dying, or the terminally ill*. She also taught me that if I were going to provide control of death to people in her situation, there needed to be *certainty of outcome, and peace and dignity in the process*.

In 1993–94, Anna went rapidly from apparent good health to a diagnosis of incurable ovarian cancer, leading to bowel obstruction and a rectovaginal fistula, and, via three major operations, to a permanent colostomy—and, inevitably, to depression and a wish to die. Dialogue about her situation, promises of support from her GP and me, and

treatment of her depression allowed her to live for another eighteen months, despite severe deafness and a sick husband. Her letters to me during this time provided me with a deep understanding of how it felt to be suffering without any hope of improvement, and to be having no one listen. She wrote: ‘It was a huge relief to talk to someone who didn’t reject my belief in voluntary euthanasia’; and ‘What the doctor sees as a good quality of life can be quite different from how the patient feels, doctors don’t see the daily miseries, and the struggle with weakness that many people face every day. Our bodies belong to us, and the law should not deprive us of the assistance of our doctors if living becomes intolerable; we have needed their help to live, and now we need their help to die’. Despite my and her GP’s promise of support, her extreme anxiety did not abate —not until she obtained the barbiturate from her family doctor that eventually allowed her to die at home, surrounded by her family. Anna taught me about the value of *dialogue, support, recognition and treatment of depression, and the reality of psychological suffering associated with a lack of control*.

In 1995, Margaret introduced me to ‘the beast’—MND, a steadily progressive paralytic illness, affecting limbs, speech, swallowing and, finally, breathing, usually with the preservation of cognition. Margaret, despite this disease, had cared for her husband after he sustained a massive stroke, which rendered him mute. When he died, she turned her attention to her own problem and sought my advice, which I freely gave. She wrote, ‘I have felt much better able to face the days ahead since talking with you. The ever present fear of being looked after in some establishment not of my choosing had been driving me into an uncontrollable depression’. I had negligible involvement in her chosen death six months after I met her, but significant involvement in the quality of her dying. From Margaret I learned *the value of engagement and support, and of talking with,*

rather than to, suffering people. I also learned that *suffering was not simply a matter of physical pain*.

In 1996, Harold was eighty-five when he suffered a brainstem stroke, which left him completely paralysed and unable to speak, but with his higher cognitive functions preserved—a 'locked-in' state. He had had the foresight to create a legal medical 'agent', his MEPA, to make decisions on his behalf in just such a situation, and had informed his son of his wishes. Yet, the neurologist in Melbourne's major teaching hospital would not comply with the agent's (and the family's) decision to cease tube feeding for Harold. On my advice, his family moved him to the hospital where I practised, and I withdrew the feeding and ensured that he died peacefully. Harold taught me the *fundamental legal and ethical duty to respect patient choice*.

In 1995, during my research into prostate cancer, I had accidently stumbled onto the subject of terminal sedation. This was a palliative care practice of gradually increasing doses of analgesics and sedatives without providing hydration until a coma state occurred prior to death—with or without the consent of the patient. Introduced quietly in the late 1980s, most Australians would not be aware of it. Because it is utilised in circumstances where many patients might also request a hastened death, and because the process inevitably ends in death, some palliative physicians have dubbed it 'slow euthanasia'. Others have invoked its 'double effect' as justification, claiming there is no intention to hasten death, only to relieve suffering. I believe them, but find it disingenuous that they reject that same intention as guiding doctors who take a different approach to relieving suffering.

Keith had terminal pancreatic cancer when he consulted me in 1998. I knew this disease well, as my father had died of it. Keith wanted to die even though his physical symptoms appeared to be well controlled. My aim has always been to try to help people to continue with their lives

for as long as they have quality of life. I engaged with Keith, seeing him weekly and providing liberal medications for relief of his symptoms, but he ended his life without my explicit advice. My support had not been enough. Keith taught me that *doctors cannot measure suffering*, and I had misjudged his suffering.

Pamela had been well until five weeks before she contacted me, in 1997. She had inoperable bowel cancer, with ascites (fluid distending the abdomen), and incipient bowel obstruction. Her descent from good health was catastrophic, and her suffering was patently obvious, being both visible and palpable. She wanted it to end, but her competent GP and her oncologist were both unresponsive. Because of her partial bowel obstruction, oral medication would have been unreliable as a means of death, so I offered her terminal sedation, which she accepted. She died forty-five hours later, but I had neglected to give her daughter the opportunity to say goodbye. Pamela taught me the *importance of the context in which people die—saying goodbye, and dying in the company of family and friends, is of great importance*. I reported Pamela's death to the coroner, who referred my treatment to the medical board. It responded, 'The Board considered that your treatment choices were not unreasonable in the circumstances and found that there was no evidence that you had been unprofessional in your conduct towards [Pamela]'.

In 1998–99, Jane had MS, but, unlike Pamela, was not terminally ill. Progressive paralysis of three limbs had resulted in her placement in a nursing home and extreme dependence. She had declining use of her right arm, which she needed to paint—her principal remaining pleasure in life. She wrote, 'I have now reached a stage where I can no longer help myself, being locked into a wheelchair, and the paralysis now reaching both hands, after total paralysis of my legs'. When she lost that hand function, she would be ready to die; she would have a completed life, she could

achieve nothing more. However, given Jane's dependence and entrapment in the nursing home, it seemed little could be done. I visited Jane regularly for eight months, during which she decided to cease eating and drinking, and I agreed to provide her with sedation, a psychiatrist having found her to be of sound mind. In hospital, she ceased eating and drinking, was heavily sedated, inducing a coma, and died nine days later. I reported Jane's death to the coroner, writing, 'Why does society impose on someone like Jane an iron obligation to choose between either a life of abject suffering and despair or an undignified death?' *Although I had helped to end Jane's suffering, I learned that there had to be better ways of dying than many days of unconsciousness*.

In 1999, Howard was suffering from secondary melanoma in the brain. He was in Catholic palliative care when he decided to cease eating and drinking, but his carers were unsympathetic and provided negligible sedation, deliberately impeding his intentions. Following his wife's intervention, Howard agreed to withdraw from formal palliative care, and, transferred to the hospital where I practised, he died under deep sedation three days later, after his family had said goodbye. I reported his death to the coroner.

I reported these three deaths, each associated with terminal sedation, to determine whether or not such deaths were reportable (namely, 'natural'). Despite the attorney-general considering that this is 'a matter of public importance', the coroner determined that if a doctor provided a death certificate, a death associated with terminal sedation was not reportable, and so would not be subject to inquiry—in other words, the doctor assisting the death would be judge and jury, provided no one complained! It was clear that the unquestioned and unquestionable intention of the doctor ruled the roost.

So, Jane and Howard taught me how readily people could become *trapped in institutions (whether nursing homes or hospices) and completely lose control over their future*.

In 2000, Helen revealed to me new dimensions. Aged eighty, she was living alone, and suffering from steadily increasing blindness, which was threatening her independence. Although otherwise physically well, she was ready to die. Her GP had confirmed her competence and endorsed her decision. I suggested a three-month waiting period in case she changed her mind, but she did not waver. She feared the future—a future of dependence, institutionalisation and indefinite duration—and feared being a burden to her daughter. This existential suffering was dominating her existence. Existential suffering may exist on its own but rarely does. It usually has a context of physical circumstances and often of psychological suffering. Helen taught me the *importance of independence, the loss of which could create existential suffering*.

Jim was a previous patient of mine who had been successfully treated for prostate symptoms. He returned in 2002 because he had developed MND. As a practical and energetic retired farmer, he found his increasing paralysis intolerable, both in a physical and an existential sense, and, as his ability to swallow was being challenged, he did research and communicated with me about his options. I have no hesitation in responding to requests for assistance from people like Jim—MND has no cure and no effective palliation. Jim died in his own home, surrounded by his family, in his own time and according to his own decision. His daughter wrote to me that ‘the whole thing was very peaceful and he looked very relaxed and didn’t appear to suffer. He was happy to the end. Looking back on the day Dad ended his life, I can only say I have very happy feelings—our memory of Dad’s death is a lot easier to reflect on than if he’d progressed further with the illness’. Jim taught me

that *with good communication, it is possible to have a good death*.

Susan was only thirty-two when she contacted me in 2003, seeking advice. She had a slowly growing, incurable brain tumour, and neither her GP, neurosurgeon nor oncologist would engage with her about her future, over which she wanted some control if it should turn nasty. Hers was psychological and existential suffering writ large, although her psychiatrist found that 'I have seen no evidence of depression throughout my contact with her. She is sad about her illness and situation but this does not equate to clinical depression'. I realised that Susan's future health depended on relieving her psychological and existential suffering, and provided her with barbiturates. She wrote to me, 'I do feel a degree of anger that the last eight years have been plagued with unpleasant thoughts and anguish needlessly. My quality of life would have been far better had the medical establishment provided me with reassurance and respected my need to maintain some sense of control'. I maintained my support for Susan for the next two-and-a-half years until she entered palliative care and died without using 'my' medication. Susan taught me many things. *Principally, she taught me the supreme palliative value of having control over the end of your life. Second, that the provision of medication does not mean that it will be used to hasten death, and that the provision of medication can improve the quality, and possibly the quantity, of life. It can actually prevent suicide. So, finally, she made me realise that my intention in providing medication was to palliate suffering, not to assist suicide. Although I could foresee that the medication might be used to end a life, this depended on the sufferer's intention*.

From 2003 to 2005, I was contacted by a couple of young men with psychiatric illnesses who wanted my help to die. One of them, Wasim, I assessed as having a treatable form of depression. I engaged him in conversation and persuaded

him to go with me to the nearest public hospital emergency department for treatment (of him, not me!). Later, Frank, who was suffering from chronic schizophrenia, rang me. He had already made two unsuccessful attempts on his life. He was under treatment, but wanted my help because he was convinced he would soon succumb in a violent way to the voices he heard. I phoned his psychiatrist to warn her of his state of mind, and learned that he was rather resistant to treatment but that further treatment options were possible. While I was sympathetic to Frank's request, knowing that renowned Australian psychiatrist John Cade had written 'depression is the most painful illness known to man, equalling or exceeding the most exquisite physical agony', Frank taught me that *psychiatric illness is the province of specialists and that I did not have the skills to assess such problems*.

Finally, in July 2005, I met Steve Guest. Steve, fifty-eight, had inoperable oesophageal cancer and was fed by a PEG. He could not swallow his own saliva, and his chest pain was dulled by morphine, at the price, as Steve said, of 'having a shot of lead in the brain'. Steve rang Jon Faine on ABC radio and railed against the Catholic Church for denying him control of the end of his life. I caught the tail end of the vigorous listener response. Steve phoned me that same evening, seeking my advice and help. His physical suffering had reached such a peak that it was now accompanied by gross psychological and existential suffering. As I drove the 80 kilometres to Point Lonsdale to see him the next day, a plan formed in my mind.

My initial experiences with counselling and assisting people like Steve had led me to fear the possibility of prosecution, but, as the years went by, police interviews took place, coroner's inquiries occurred and public admissions were made without any apparent interest from the authorities. I had begun to think that the prosecutorial authorities were not interested in pursuing doctors who

were providing advice and assistance to people whose lives were ending, given no one complained. I called it a ‘benign conspiracy’. It occurred to me that a more deliberate challenge to the law as it stood—or as it was ignored—was conceivable. It also seemed desirable to seek a change to the law through the judicial process, given that parliaments were proving reluctant to grapple with the issue.

Two criteria seemed to me to be fundamental to such a challenge—first, that it involve a person who was dying, which was causing suffering that was palpable and unrelievable; and, second, that their story was known to a wide and supportive public. Steve Guest seemed to be such a person. My prolonged talking with him satisfied me on the first point, such that I had no hesitation in providing him with Nembutal as a palliative for his otherwise unrelievable psychological and existential distress, while being fully aware that he might use it to end his own life. After, and only after, I had provided Steve with medication, I explored his interest in a media campaign. I was confident that being involved would give him a sense of purpose for the remainder of his life, and enhance its quality and meaning. He jumped at the idea, and that is exactly what happened. Steve gave numerous print and radio interviews in the last two weeks of his life, and was intimately involved in an SBS documentary, *Do Not Resuscitate*; most memorable was his one-hour discussion with Jon Faine on 18 July 2005. He died on 26 July in the company of his brothers.

I subsequently made a number of provocative statements on radio and television regarding my involvement in Steve’s death, resulting in two police interviews, but no other action. My conclusion about there being a benign conspiracy had been borne out. It was not until 2014 that I finally admitted I had given Steve Nembutal—there was another police interview but, again, no action!

Engaging with Steve confirmed many things I had previously learned. He made it clear that suffering was not

simply physical, and that psychological and existential issues were intimately involved with quality of life. He made it clear that having control over the end of one's life was of critical importance to some people, and that many wanted to control it in their own homes, rather than die in a prolonged coma in an institution. And he proved to me that it was possible to challenge the prosecutorial authorities and emerge unscathed—that there was innate reluctance to pursue a doctor who was acting carefully and ethically to provide compassionate assistance to competent people in ending their lives. A surprise? Not really, it's a no-brainer when you think about it. The surprise is that it has taken parliament so long to respond to the message its agencies and the public are sending.

Above all, Steve confirmed for me the enormous palliative value for people in having control over the end of their lives. Rather than necessarily hastening death, it can prolong some lives, and may prevent violent suicide.

After *A Good Death* was published in 2008, law professor Roger Magnusson invited me to deliver an oration to the Sydney University law faculty, based on the book. In preparing the oration, I developed the concept of six 'medical givens', or self-evident truths: unarguable medical statements about the end of life. They are critically important to the argument for the necessity for medical assistance in dying.

First is the fact the some dying people experience intolerable suffering, which may escalate as death approaches. A journey through the voluminous palliative care literature leaves you in no doubt about the frequency and multiplicity of troublesome end-of-life symptoms, many of which cannot be adequately relieved and may crescendo towards the end.

The second is that some suffering will only end with death. You need only talk to any experienced nurse, or someone who has cared for a relative at the end of their life,

to hear of the relief from a ‘merciful death’, or to hear the phrase ‘Thank God that’s over’.

The third is that doctors have a duty to relieve suffering. This has been the essence of medicine from the time of the first physicians, when curative tools were negligible. With most illnesses, the body cures itself while the doctor relieves the symptoms. Modern medicine has many more curative tools and doctors tend now to see themselves as great healers, but the relief of suffering remains at the heart of good medicine. It is the doctors’ ethical imperative.

The fourth is that palliative care cannot relieve all the pain and suffering of dying patients. This comes from Palliative Care Australia’s 2006 position statement and is essentially correct if you ignore the palliative practice of terminal sedation, which has at least the potential to hasten death. But, of course, palliative care does not, on principle (based on its religious and philosophical underpinning) hasten death. So those involved with palliative care do not publicly talk about terminal sedation, and when challenged about it, deny that it ever hastens death, if it is properly and proportionately titrated.

Next is the recognition that some dying patients persistently and rationally request a hastened death. This is again from the 2006 position statement, and the statement is fully supported by many years of experience.

Finally, it is accepted that doctors have a duty to respect their patients’ autonomy. This is a relatively recent development in medical ethics. When I graduated, in 1959, medicine was decidedly patriarchal. Patients largely did as they were told and asked very few questions. With the steady spread of human rights, social services, feminism and rising living standards, together with increasing legal protection, the whole doctor–patient relationship shifted. The development of bioethics, and the training of doctors in this discipline, has gradually led to the primacy of the patient’s view in treatment decisions. Bioethicists Douglas

Martin and Peter A Singer and physician Linda Emanuel stated in 2000 in *The Lancet* that ‘the principle of autonomy is the dominant ethic of health care in North America and Western Europe’. However, although this ethic is now accepted legally and by many doctors, there are still some conservative medical practitioners who only pay lip service to it, and many are still reluctant to cede decision-making power to patients.

If you put all these truths together, a doctor may be treating a dying patient experiencing intolerable suffering that is escalating, and may only be relieved by their death. If such a patient asks persistently and rationally for assistance to die and the doctor respects their autonomy, that doctor faces a serious ethical dilemma, with serious legal ramifications that are in apparent conflict with the ethics. For me, ethics have defeated the law because the law is unjust, threatening to doctors and harmful to patients.

From my experiences in 1974 to 2005, as partly detailed in *A Good Death,* I have determined something else, which is self-evident to me but not generally appreciated by those without such experiences, which is almost everybody. It is that the provision of control over the end of life is the most powerful palliative for people approaching it or for those battling unrelievable suffering due to chronic, incurable illness. The peace of mind and sense of security it provides are profound, and do not in any way dictate that medication that can be used to end life will be used for this purpose. If it is, it provides a secure, peaceful and dignified end to life that can be warmly shared with those closest to the dying.

The vast majority of stories in *A Good Death* are about people with cancer who were within weeks or months of death, but some of the stories are about people with neurological illnesses, who, while having a terminal condition such as MND, were not necessarily within weeks or months of dying. Four of them (Alice and Jane, who had MS, Helen who had MND, and Susan who had a brain tumour)

certainly were not. They had what I described in that book as a *hopeless illness,* but what I now call an advanced incurable illness.

These experiences, and my further, expanded, experiences with people suffering from advanced incurable illnesses, have altered my original reluctance about wider access to assisted suicide. I now believe the means to control the end of life should be available not just to the dying but also to those experiencing intolerable suffering from incurable illness.

3

COUNSELLING

It should be no surprise that dying people have profound psychological and existential concerns. Counselling is paramount in the care of people who are at the end of life. When the Voluntary Euthanasia Society of Victoria—now Dying With Dignity Victoria (DWDV)—was formed in 1974, by a group of humanists, one of its statutory aims was the provision of individual counselling to members with specific end-of-life problems.

When I joined DWDV, in 1992, I was one of the first doctors to do so, and was persuaded to join the board. I was immediately drafted into the role of counsellor, as it had been difficult for members without a medical background to provide good advice, because of the complexity of the issues and their inability to offer any practical solutions.

I had not had any formal training in counselling, but had developed the view that a medical consultation was not just about a diagnosis and treatment advice, it was also an opportunity to teach the patient about the body’s function

and the causes of symptoms, and to discuss simple, conservative remedies other than surgery. My urological practice had evolved into one reflecting my significant interest in sexual dysfunction, in which psychological disturbance is common, so its treatment involves counselling skills. I developed these on the job.

Shortly after I assumed this role, an article appeared on the front page of the Sunday *Age* with the headline ‘I helped patients die’, naming me and including details of an interview that I had naively given to a journalist. From that time, I began to receive letters, emails and phone calls from distressed people who were desperate to talk about their fears and their suffering as they approached the end of their lives. Most of these people were not DWDV members, but I could not ignore them. I responded to every approach, and thus began a new medical career as an end-of-life counsellor. This involved enhancing my skills in listening to and talking with (not to) people who were often in great anguish. This work took a lot of time and patience, but much of it proved the most gratifying of my whole medical career.

It was not unusual, and very rewarding, to hear someone say at the end of a counselling conversation, ‘It is just fantastic to be able to talk to someone who will listen to my problem and understand my concern.’ Such comments made it very clear that the person’s usual doctor did not want to listen or get involved in any way, so they were unable to have ‘the conversation’ about dying. Sometimes a single conversation was all that was necessary and no specific prescription advice was needed—the knowledge that there was someone who would listen was enough. On many other occasions, this first conversation was the start of a supportive dialogue that would go on for many months, and sometimes years.

As a result of this counselling, I became a better urologist, a better doctor and a better person, because I

developed not just my listening and communication skills, my empathy and my compassion, but also my analytical skills, so as to determine the best approach to difficult issues. It was a minefield because people were asking me to help them in ways that at that time were almost universally considered criminal. Then, and today, the Victorian Crimes Act 1958 mandated five years' imprisonment for aiding and abetting suicide. Exactly what aiding and abetting suicide meant in practice was unclear, but it was generally accepted that advising someone about committing suicide, or, more particularly, providing medication to facilitate it, was criminal behaviour. The words of writer Jeanette Winterson apply to this period*:* 'There is no discovery without risk, and what you risk reveals what you value'.

For many years I was petrified about having end-of-life conversations by phone (so, usually, were the callers), and if specific advice was needed, a public phone box or a private number other than mine would be used. Gradually I realised that the provision of advice alone was unlikely to be criminal, and that to be guilty of aiding and abetting suicide, some physical assistance or prescription was necessary. If the person's condition was serious, a personal interview, examination and intense dialogue were essential.

As the number of such contacts grew, I realised that their details could prove to be a valuable research—or, at least, information—tool. So I devised a pro-forma document to record the details of each request for counselling. These included their age and sex, the diagnosis, information about the preparation of a MEPA and advance directive, their symptoms and treatment, family structure and involvement, and the nature of the request. This has proved a valuable resource, allowing assessment of the frequency of requests for advice over time and the incidence of various medical conditions leading to requests.

I started this record keeping in 1996, and over the next six years there were forty-one requests for counselling. In a

single year, 2002, this jumped to forty-four, and there was a gradual escalation, with sixty-six in 2007, and seventy-eight in 2008. Numbers, at fifty to seventy, fluctuated between 2009 and 2014, but in 2015 spiked to 99, and by the end of August 2016 to 118 (which represents two-to-three engagements a week).

Clearly, the incidence of requests is increasing, but the pattern is interesting. There is almost always a flurry of contacts following a significant media 'event' around end of life, particularly when I have made public statements, or written articles or had other media exposure on the matter. The spike in numbers in 2008 was associated with the publication of *A Good Death.* Another spike occurred in 2014, when I stated publicly that I had provided oesophageal cancer sufferer Steve Guest with Nembutal. In October 2015, I appeared on the popular ABC television program *Q&A,* again saying that I had provided Nembutal to people, particularly those with MND. I received forty-five contacts over the next three months. Seven of them had MND, and I provided all of them with Nembutal, since there is no other effective palliation for this dreadful disease. In March 2016, I appeared on another popular ABC program, *Australian Story,* in which I indicated my support for Bernard Erica, who was suffering from incurable throat cancer. In the next ten weeks, I received forty-eight requests. I provided medication to five of these people, three of whom had MND.

I do not advertise my 'services' (except in the broad sense of advocating for a change in the law) and do not solicit 'customers'. These people contact me out of desperation, or from a desire to be prepared for their future, whether known (if they already have a fatal disease) or unknown. There has been a gradual increase in medical 'referrals'. These may be direct communications from doctors who share my philosophy, or be via referral letters about a urological complaint that proves not to be the real reason for the referral (a 'blind'), or be verbal suggestions by

a doctor to a patient that they consider contacting me about their problem (no risk taken there).

The conversations that arise from these contacts are usually complex, prolonged and difficult, stretching my compassion, imagination and courage to their limits. There are often many discussions and may involve potentially serious risk-taking on my part. On other occasions, the people who contact me are well, and simply want information, and, often, medication to store for a rainy day, but I do not provide this. I do not charge people for any of this advice—it is pro bono, except when people arrange consultations in my office, as I incur costs from this process; I then charge a fully rebateable Medicare fee. I am happy to help people but do not feel I should be financially out of pocket for doing so.

My reward for this difficult and unprofitable work? It is receiving letters such as this:

> Thank you very much for listening to me. And for your understanding and advice. It is such a relief and comfort to be able to talk openly and freely about such a basic thing as a decision to die with dignity. I draw immense comfort from knowing that I have a choice to die if I face a quality of life that would be unbearable to me. As I face every new day I am reassured by the knowledge that if my life becomes too difficult I can leave at any time. It is as if the possibility of dying by choice extends and improves the quality of my life by giving me peace and acceptance, and being less troubled by unexpected and unacceptable complications and sufferings to come. It is bad enough having terminal cancer not knowing when and which new complication will occur, how my life quality will be affected and how much time is remaining—without having to worry about dying without dignity. I want to avoid any unnecessary suffering in the little time I have left.
>
> The cancer has gone to my brain. I have finished a 4 week course of brain radiotherapy and am still suffering serious side-effects. Therefore being able to talk about the possibility of dying with dignity and choosing the time and place to do so, and knowing there are means to do so, has brought peace and relief in my stressful life as a terminally ill person. At least, I think, the end will be peaceful and of my choosing.

An analysis of the types of conditions that the people who contact me are suffering from yields fascinating results,

which are almost certainly not what most people in the community would expect. There are figures from the Netherlands showing that of people receiving euthanasia from their doctor, 70 per cent are suffering from cancer and 6 per cent are suffering from MND (although these are 20 percent of all MND deaths). However, in the Netherlands in 2010 only 45 per cent of requests for assistance with dying were complied with, leaving the obvious question what are the other 55 per cent suffering from, and why are their requests declined?

My analysis of the requests I have received are divided into eight categories.

Cancer

Cancer is not difficult to categorise in principle, but the stage of the cancer people were suffering from was extremely variable, ranging through the following:

(a) A very recent diagnosis, and before treatment (a state of ‘cancer shock’). Sometimes this is associated with a quite reasonable determination to refuse any treatment, particularly in an old or frail person.

(b) A recent diagnosis, and after treatment. If the outcome of the treatment is said to be good, there may be discussion around ‘What if it recurs?’; or if the outcome is poor, the question is ‘Will you help me?’. The answer is ‘Keep in touch—let’s talk again if things turn sour.’ Most of these people I do not hear from again. The supportive dialogue and making a connection are enough.

(c) An established diagnosis of metastatic (secondary cancer that has spread to another part of the body) and probably incurable cancer, but no currently intolerable symptoms. Again, the question is ‘Will you help me?’ These people do not want help now—they want reassurance, to talk to

someone they can trust. The answer is ‘Keep in touch—let me know how things are progressing.’ A number of these people do follow up with me. At this time it is important to encourage them to engage in dialogue with their families (and/or friends), to explain their suffering (which is not always evident) and bring them to a full understanding of what they are contemplating and why.

(d) Widespread disease that is not responding to treatment, associated with increasing physical, psychological and existential suffering—these people are either in the ‘terminal phase of a terminal illness’ (they can readily be seen to be dying, possibly within two months, and probably less). The answer is to seriously engage with them, explore every aspect of their illness, their treatment, their psyche and their values; and to ensure that the important family discussions mentioned above have taken place.

(e) In some instances, a current cancer that was in remission, or even possibly cured, was part of a more diverse request associated with old age and frailty, or another system disease and disability.

Neurological disease

Again, neurological disease is reasonably easy to categorise. It comprises primarily degenerative neurological disease, but also some brain cancers, either primary or secondary, present with predominantly neurological symptoms. The most significant neurological symptom is paralysis, although interference with communication and change in personality may also be disastrous. I have subdivided these symptoms into four categories:

(a) Progressive paralysis such as that caused by MND, with rapid, life-threatening deterioration towards the end,

when bulbar functions (speech, swallowing, breathing) are affected.

(b) Progressive paralysis over many years but without any specific end point, such as that which occurs with MS. There is often disturbance of bladder function and of vision, but cognition is spared.

(c) Slowly progressive dysfunction of movement and speech, and often cognitive impairment (as with Parkinson's disease).

(d) Sudden paralysis, such as with traumatic quadriplegia, or a profound stroke,which is not progressive.

The frail elderly

This group consisted of elderly people, usually aged over seventy-five, who were suffering in various degrees from the degenerations of ageing. We humans are not built to survive much beyond 100 years, and progressive deterioration occurs as we age, and tends to accelerate, or have greater impact, over the age of seventy (the biblical three score years and ten). There is commonly, but variably, deterioration of eyesight and hearing, the senses that most allow communication. There are not infrequently challenges in varying degrees to the continence of the bowel and bladder, which can be the grossest indignity for many people. There is progressive loss of mobility and dexterity, due to joint and spinal degeneration, and loss of muscle mass and power, together with loss of balance leading to a tendency to disastrous falls. Confinement to your own home or a nursing home, or just a room, or even to a bed and chair, may be the outcome. Finally, there is the progressive loss of cognitive function, even without a specific dementia diagnosis.

All of these problems, which I call the ‘five horsemen of the ageing apocalypse’, further challenge independence, and force many ageing people into institutional care. It is usually abundantly clear that the person sees institutionalisation as a disaster. These problems are all far worse when you are alone, and so tend to affect women more than men, because they often outlive their partners.

It is not unusual to find that these people have a history of cancer, or of cancer that is in remission, with the associated fear of its return. They are often in chronic pain from their degenerative spine and joints. Not unnaturally, they may have psychological distress to varying degrees—significant anxiety about their future, and the, almost universal, fear of being forced into institutional care. Degrees of reactive depression (adjustment disorder secondary to their circumstances) are not uncommon. This is not surprising, as 50 per cent of nursing home inmates suffer from a depressive illness. Some of them may actually have varying degrees of dementia as well.

Chronic organ failure

The vital functions of the heart, lungs, kidneys and liver can also degenerate, but failure is usually associated with chronic disease, and can occur at a much earlier age. People with chronic organ failure usually have a slow trajectory to death, often over years, but punctuated by episodes of acute failure that may be life threatening. With modern medical care, survival is common, meaning a return to the distress caused by the chronic illness. This is a very different trajectory from the dying process with cancer, where quality of life may be reasonably well maintained until a few months before death. The slow decline associated with chronic organ failure may last for years; the distress may be just as severe as with cancer but last very much longer.

Chronic pain

Modern medicine does many things very well, but its ability to manage chronic pain is poor. Acute pain can be well managed with analgesics, but chronic pain is associated with tolerance to strong analgesics and addiction with prolonged use (with which side effects are a problem). Chronic pain is not unusual with spinal injuries, joint disease and degeneration, especially for people with rheumatoid arthritis, which can affect many joints. Chronic pain is not limited to the musculoskeletal system but can derive from the bladder or bowel, and sometimes appear as a ‘headache’. I fail to understand why a severe pain in the head should be diminished by calling it this. Living with chronic, poorly relieved pain is one of life’s greatest burdens, and is often associated with reactive depression and a sense of hopelessness. This is not difficult to detect if you are looking for it, but almost impossible to treat. Such chronic but untreated pain is acknowledged to be common in nursing homes. For many suffering this way, work is impossible, sexual dysfunction is not unusual, and dependency and relative poverty the outcome. It is not surprising that some find the burden of life too great. While these people do not have a terminal illness, their suffering may be as severe as if they did but have no end in sight.

Psychological illness

A small number of people seek help from me because of purely psychological illnesses. Frequently, it is depression, or bipolar disease, but could be schizophrenia, or the recently named post-traumatic stress disorder. Almost always, these are people who have suffered from their illness for years, and had treatment without significant benefit. Many have ceased treatment. Sometimes they present with a facade of vague physical symptoms, but it is relatively easy to pierce that veil. I advise these people to seek specialist treatment,

even though they feel they have exhausted the possibilities of such help. Occasionally I am overjoyed to receive a call from someone I have advised to seek further advice and treatment, and to find out their problem has been resolved.

Dementia

Requests relating to dementia are usually from distressed relatives who have a loved one in care, totally dependent, unable to recognise them or communicate, and often with untreated pain. Occasionally there will be contact from someone in the early stages of dementia who still has mental competence and who does not want to go further on their journey to a vegetative state.

Miscellaneous

This is a mixed bag of requests with no common denominator. Many of the people are quite well and looking for advice on a possible future. Some of them want medication to store for a rainy day. Some do not have any definable illness, but a vague mix of pain and psychological illness. Others are ringing me on behalf of a friend or relative. It should be emphasised that significant discussion only takes place with the suffering person, not with a surrogate.

The incidence of requests

The incidence of different categories of requests varies from year to year, but over the twenty years of records has remained relatively constant:

Cancer	32%
Neurological	14%
Chronic organ failure	7%
Chronic pain	7%

Frail elderly	20%
Dementia	7%
Psychological	7%
Miscellaneous	6%

What is striking about these figures is the nearly 30 per cent who are the frail elderly or who have dementia. It is an indication of the level of distress felt by such people, but whose voices are rarely heard in the end-of-life debate, largely because they have lost their voices, and have no one to represent them; yet, they are the fastest-growing group of those who are approaching the end of their lives. At present, everyone else is making decisions for them—no one seems to be asking them what they want.

Of the people with cancer, many of those in the earlier stages I only heard from once. They would say, ‘Doctor, it is just fantastic to have someone to talk to, who understands and will listen to my concerns.’ This highlights the difficulty many doctors have in discussing openly such concerns of their patients. Many, as I say, are comforted by having been heard, and given an invitation to get in touch if or when things deteriorate. They do not need practical assistance at this time, merely compassionate support. Most do not make contact again because their disease has not progressed as they had feared.

Some of those with cancer are at an advanced stage, with intolerable suffering that cannot be relieved. Some are in palliative care but are not comforted. Many of these people are desperate for control over the end of their lives, and providing such control is often of massive benefit. Susan, who was not terminally ill when I gave her a barbiturate, had it for two years and did not use it in the end. Steve Guest had such significant relief that he waged a media campaign for over two weeks until extreme fatigue overcame him. Some, though, are in such distress that they

use it immediately, such as Len, who suffered intolerably from bladder cancer.

What these experiences have taught me is that requests for assistance and advice come in a wide variety of contexts, and each one needs to be given individual attention. My underlying principle is to try to assist everyone to go as far as possible with living, but not to subject anyone to suffering they cannot tolerate. We are all different, in our characters, life experiences, stoicism, mental strength, fundamental beliefs, personal supports and resources, and our ability to persist in great adversity. As a doctor, I cannot measure my patient's suffering—it is arrogant in the extreme for me to say, 'Your suffering is not sufficient for me to assist you.' I will always explore the possibility of a correctable physical, psychological or social component, which, if relieved, would alter a request being made, but if none is apparent, I must take my patient's request very seriously.

Overlying the characteristics giving rise to a request are the stage of the disease, and social and age components. Some cancer patients, for example, request advice at diagnosis. They need reassurance, encouragement to engage in treatment, and an offer of continued dialogue if necessary. Some have had treatment but are unsure of the outcome; in that case, much the same advice applies, but with additional counselling to begin preparations for their future, such as creating MEPAs and advance directives, and to commence open communication with family and doctors. If they have recurrent cancer, they need more urgent advice, to prepare important documents, learn more about their disease, ask pertinent questions about treatment, and communicate—persistently and frequently—with their family and doctors about their symptoms and wishes for future treatment. At this point, a commitment to provision of control, if needed, usually has powerful palliative value. The next phase is the 'terminal phase of a terminal illness',

where a person is dying and death is imminent, or actually predictable (difficult to do with more accuracy than estimating a month or less). The South Australian Consent to Medical Treatment and Palliative Care Act 1995 defines the terminal phase of a terminal illness as ‘the phase of an illness when there is no real prospect of recovery or remission on either a temporary or permanent basis’. In this circumstance, actual provision of controlling medication has the ultimate value, but should always be accompanied by inclusive discussion with the family, if at all possible.

The age and social circumstances of a suffering person are significant here. A mother with young children and a loving husband is highly likely to want every drop of life she can have, and will undergo any distressing treatment, irrespective of likely outcome, and needs the most empathetic and sensitive support. On the other hand, a widow of advanced years with no family may reasonably have no desire to undergo chemotherapy with little prospect of success but a significant prospect of side effects. Again, sympathetic and sensitive support is needed, but with a different nuance.

It is apparent that some of these people are actually dying when they make contact. Their death is imminent, can be clinically determined as occurring within a month or less. People with incurable cancer and who are no longer responsive to treatment are on a trajectory to death that is reasonably predictable.

On the other hand, many have a slow and undeterminable time until death. There are progressive neurological diseases, such as MND, MS and Parkinson’s disease, that can cause great unrelievable suffering, with a variable and unpredictable trajectory. In addition, there are tragic, sudden and massive neurological events that, having occurred, can remain static for years, such as spinal injuries (quadriplegia) and severe stroke, and a variety of,

fortunately unusual but extremely difficult to treat, neuralgias.

In addition to this group are those with chronic organ failure such as that of the heart, lung, kidney or liver, whose trajectory (if not interrupted by a transplant or kidney dialysis) is usually slow and unpredictable. Many of them are walking a fine line with death, waiting for a sudden, potentially lethal complication. However, with marvellous modern medical treatment, they recover, only to progress slowly downhill. Their time until death is highly unpredictable, yet they may experience considerable chronic suffering.

Then there is the group of people with severe and unremitting pain who do not have a terminal illness. These are predominantly musculoskeletal disorders of the spine and joints, such as chronic spinal injuries unresponsive to multiple surgeries, spinal osteoporosis and vertebral collapse, and chronic rheumatoid arthritis. The latter has caused some of the worst pain I have ever encountered, when multiple damaged joints make any movement at all excruciating.

These latter three groups do not have a terminal illness or a predictable death trajectory—they cannot be determined to die within ‘weeks or months’. As such, they are at least theoretically excluded from the proposed legislation for Victoria (see Chapter 12), or legislation in the United States (where the relevant period is that of less than six months to live). They have an *advanced incurable illness*, and while their suffering may be just as intolerable as that of those who are terminally ill, their suffering will in many cases last for a very long time. As Yale Kamisar, an American emeritus professor of law (and actually an opponent of assisted dying) said in 1996, ‘If personal autonomy and termination of suffering are supposed to be touchstones for PAS, why exclude those with non-terminal illnesses or disabilities who might have to endure greater pain and

suffering for much longer periods of time than those expected to die in the next few weeks or months?'

Much of the argument in this book, though, focuses on the issue of those with an advanced incurable illness.

The fundamental principle of good counselling about end-of life-decisions is open and transparent communication, with the suffering individual at the centre of the discussion. Anatole Broyard, essayist and former editor of the *New York Times Book Review*, wrote eloquently about the psychological and spiritual challenges of facing metastatic prostate cancer.

> To the typical physician my illness is a routine incident in his rounds, while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity … I just wish he would give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way.

This is a standard complaint, highlighting a lack of both the time and of commitment by doctors to engage with patients (from the Latin word 'patiens', which means to endure, bear or suffer). Good counselling takes time, as much time as is needed to resolve the issues, and may require dialogue over a prolonged period. Hence, it is not popular with busy 'technical' or 'procedural' doctors. It may take more time than the procedure that has led to the need for counselling, but does not pay as well, and may actually be more difficult until the appropriate skill is acquired. This too takes time and practice, with introspective assessment of the outcome. At the end of an effective dialogue, the informed suffering person owns the decision, and is not forced to 'share' it with the doctor. That is the essence of patient autonomy.

To counsel well, you must get to know something about the person and their family structure, their illness and the relevant treatment, the current state of the illness, their current treatment, and the symptoms they are suffering. All

this time you are assessing the person's state of mind (for example, anxious, depressed or calm and realistic), and their state of competence in understanding and responding to questions. It is about determining what they want, how long they have been thinking this way, their state of readiness for death, and ascertaining it is their view that is being expressed. For me, it is critical to determine what dialogue they have had with their family, and to encourage this if it is absent, or strengthen it if it already exists. Further, it is vital to ensure that the relevant documents such as legal surrogate decision-makers (MEPAs or agents) and advance directives are completed. It is necessary to ensure that the person has a sound understanding of their illness and the law surrounding end-of-life practice, has established good communication with their family and doctors, and has come to a realistic acceptance of their situation.

Years of counselling have revealed to me that many people reach a state where they are ready to die, which means they would be content if they did not wake in the morning but are not actively seeking to bring their life to an end. Many have what I call a 'completed life'—they have nothing more to achieve; in fact, there is nothing more they can achieve, due to their condition. They are waiting to die. Some, usually those experiencing more intolerable suffering, have reached their time to die—they want to say goodbye and end their suffering. From this point until they die 'naturally', either from their disease or from traditional medical interference in the end of life, their suffering increases and is intense. The longer this period, the worse the suffering.

I suspect my counselling experiences are the tip of a very large iceberg. They represent only those people who have somehow heard of me, and had the courage and determination to further pursue their end-of-life choices by contacting me.

My counselling journey has been one from naivety to a deeper understanding of suffering, and what suffering people want. This is not necessarily to die, but to be relieved of their suffering in an effective and humane way. Even if it means ending their life.

After twenty-five years of end-of-life counselling, it is clear to me that open communication between a suffering person and their doctor can have a powerful palliative effect. Such discussion ranges from the patient's values, their symptoms, the likely course of their disease and the available palliative treatments, to the involvement of the family, and must include the option of hastening death.

Frances Norwood is an American anthropologist who for three years investigated euthanasia by Dutch GPs. She described what she found in a powerful book, *The Maintenance of Life.* It is subtitled *Preventing Social Death Through Euthanasia Talk and End-of-Life Care—Lessons from the Netherlands* and describes the enormous palliative value of 'euthanasia talk'. The positive effect of patients being able to talk openly (and legally) with their GP about the possibility of an assisted death is immense. On the majority of occasions, euthanasia is not the outcome, but 'talk about euthanasia may be seen as having a palliative function, even prolonging life while discussion about it goes on, and keeping the patient alive enough to think about what their life has meant and continues to mean, and the circumstances in which they would or would not be content to live … Most of the people I talked to did not want to die, but considered euthanasia an ideal option in the event that their suffering became unmanageable. Euthanasia requests were not wishes for death, but more generally an insurance policy for the future'. Exactly—it is what I describe as the 'key to the fire escape'.

4

ADVANCED INCURABLE ILLNESS

The idea of hope, or lack of it, is riddled with subjectivity. In *A Good Death,* I used the term ‘a hopeless illness’, which I defined as ‘as an incurable illness of certain permanence or inevitable progression whose severity causes intolerable suffering which cannot be relieved by treatment that is acceptable to the sufferer’. While that is a reasonable description of the circumstances of a certain group of people, the word ‘hopeless’ has a degree of subjectivity that allows it to be misunderstood.

I have had opponents of assisted dying say that diabetes mellitus type 1 diagnosed in a sixteen year old is an incurable illness, and that the above definition would allow them to be construed as having ‘a hopeless illness’. More precise wording was needed, and I decided on ‘advanced incurable illness’. Many illnesses are incurable, but it is usually only in the advanced stages of the illness that significant suffering is likely. Take the example of diabetes—it is not cured by insulin replacement, but people who have

the disease can live comfortably for many years, though eventually chronic damage to blood vessels and nerves causes cumulative damage, and often distress in the advanced stages of the disease.

I define advanced incurable illness as a severe, permanent illness with no predictable timeframe until death, which causes significant, unremitting symptoms, and no effective treatment is available to alter the course of the disease or to relieve the intolerable suffering. Its course may be either remorselessly progressive or static.

Why does such a category as advanced incurable illness need to be considered? The answer is simple and logical—because intolerable suffering, if unrelievable, is not confined to the terminally ill, or, more specifically, to someone who is clearly seen to be dying. It also occurs in chronic illness.

The fundamental role of a doctor is to relieve suffering. If the doctor is able to cure a disease, they will obviously relieve, or end, any suffering associated with that disease. However, sometimes the cure comes at a cost of later disability (as per the expression ‘the cure may be worse than the disease’). More often, the body cures the disease, while the doctor may shorten the course of the illness and palliate the symptoms until a cure is achieved. Palliation is defined in the *Oxford English Dictionary* as ‘to make the symptoms of a disease less severe without curing it’.

The concept of doctors being ‘healers’ is overblown—they are, more usually, modifiers of disease. Almost no surgery would be possible without the added component of the body’s capacity to heal. If, as is quite common, the doctor cannot cure the disease, they attempt to control or modify its course, all the while minimising or palliating the symptoms in order to relieve suffering. The modern concept of palliative care as a special group of palliating doctors and nurses is rather strange, because this is fundamental to what medicine has done throughout history.

Palliative care came about for a number of reasons. Prior to World War II, doctors had very few curative tools, apart from some surgical operations. However, anaesthesia was still crude, surgery had to be quick and mortality was significant. Every war in the past 200 years has led to major improvements in medicine. Examples include early amputation to prevent gangrene in the Napoleonic Wars; the development of modern nursing in the Crimean war; blood transfusion in World War I; improved anaesthesia and antibiotics in World War II; and rapid evacuation, triage and early intervention in the Vietnam War. Following World War II, the development of a very wide range of new pharmaceuticals, antibiotics and life-saving or life-prolonging techniques (such as artificial ventilation, dialysis and transplantation) meant that many people who would previously have died at home were referred to hospital, and died there—badly, in some instances—in the hands of unfamiliar doctors, rather than in those of their familiar general practitioner. With the advent of antibiotics, pneumonia (known as the ‘old person’s friend’) was conquered, and having a natural death became difficult.

Dying moved from the home to hospital, where doctors were determined to keep their patients alive and medicine’s default position was to treat if treatment was available. For a thankfully short period, until reason prevailed, most cardiac arrests in hospital were resuscitated with cardiopulmonary resuscitation (CPR); much such resuscitation was predictably futile, and brutalised an inevitable death. Dying with any dignity became extremely difficult. Death was regarded as a failure of medical treatment, but even when a medical team did acknowledge that there was no more curative treatment, they did not know what to do next.

Palliative care filled this gap. The skills required were not high level, and no special training was necessary, only a sound knowledge of palliative medications, empathy and good communication skills. However, there was no

undergraduate training, so you had to learn on the job, and the subject matter of the communication was difficult. Many doctors did not want to engage with their patients about dying, and were happy to leave this to others.

Between 1900 to 2000, average life expectancy rose from fifty to eighty years. Rather than dying quickly, predominantly from infections, people now die slowly from chronic disease and old age. The incidence of cancer as a cause of death rose from 5 per cent in 1900 to more than 30 per cent in 2000, and is the commonest cause of death in western countries. Alzheimer's disease, first described in 1906, is now the third most common cause of death in western countries. The increase in these two diseases demonstrates the incredible change in the way we die over the past 100 years.

Joanne Lynn, an eminent American geriatrician, hospice physician and philosopher, has clearly defined the modern trajectories to death, and categorised three broad groups (apart from sudden death): cancer, chronic organ failure, and degeneration and old age (with June Lunney et al, the *Journal of the American Medical Association*, 2003). The symptoms of cancer, even if incurable, can generally be well controlled until the final phase of the disease, the terminal phase, when a fairly rapid and steep downhill trajectory to death occurs, often over about six months or, frequently, less. In chronic organ failure, there is a much slower trajectory to death, often over years, punctuated by acute episodes when death is possible; but, due to aggressive medical treatment, survival is common, with a return to baseline or a little below it. You cannot accurately assess when these people will die—it may take days or years. While they may be terminally ill in a real sense, with an illness that will not get better, from which they are highly likely to die, they are not in the final phase, their time of death being unknown. The third group, victims of age and degeneration are also dying, but slowly and uncertainly, with a

frightening, prolonged decline in bodily functions, but not necessarily of any vital organ, so that they may go on and on suffering slow decay, until death quietly, and often unpredictably, occurs in their sleep. This process is common in our aged care institutions. The people in this group can be described as having a completed life and many are ready to die.

Put very simply, the change in the way we die is the most fundamental reason for both the rise of palliative care and the demand for assisted dying. Serious consideration of both concepts developed in the late 1960s, and for similar reasons: to treat dying people with respect, to humanise the dying process, and to relieve dying people's suffering. But the schism was there from the beginning. Dame Cicely Saunders, the medical founder of palliative care (the hospice movement), a devout Christian, was from the start adamantly opposed to assisted dying. This religious position has been the fundamental wedge between these two groups ever since.

Many might see the heart as the body's most vital organ, but in fact almost every organ system in the body must function properly for it to stay healthy. If any of these systems fails badly, severe suffering usually follows.

We need an intact skin to protect us against infection from the environment, or excessive fluid loss, as occurs with burns. Our skin is very sensitive, and extensive damage to it can lead to excruciating and persistent pain. Janet Mills was the second person to die in the Northern Territory using Marshall Perron's Rights of the Terminally Ill Act 1995. She was suffering from mycosis fungoides, an ulcerative malignant condition, affecting most of her body, and that caused intolerable and unrelievable itching. Continuous discharge from malignancies causes what sociologist Julia Lawton calls 'the unbounded body' (*The Dying Process: Patients' Experiences of Palliative Care*). Lawton spent six

months in a British palliative care unit in order to understand what occurred in it.

The heart is, of course, of fundamental importance, though, and diseases of the cardiovascular system are the most common cause of death in Australia, being slightly more common than all cancers. Many of these deaths are acute or semi-acute (for example, due to stroke, cardiac arrhythmia or myocardial infarction) but a significant number are due to chronic heart failure. Cancer specialist Martin Cohen and his associates found that 'the quality of life in chronic heart failure is poor, and discomfort and distress often worse than cancer. People who died of heart disease had experienced a wide variety of symptoms, often distressing, and often lasting more than six months. At least one in six had symptoms as severe as those with cancer managed in palliative care services' (*Cancer Investigation*, 1992). So, here we have an advanced incurable illness that produces suffering that may be equivalent to the suffering resulting from cancer, but that may last very much longer.

Columnist Paula Span told the story of Rae LeRoy ('Wounded by the language of war', *New York Times,* 11 April 2014):

> In late January Rae LeRoy, 93 and still active and living alone, developed difficulty breathing. She was diagnosed with heart failure, and was treated, initially 'successfully'. But one hospitalisation followed another, 911 calls, release to rehabilitation and re-admission. Each hospital stay left her further weakened. Her longtime doctor resisted any suggestion that active treatment might be ceased in favor of comfort care, saying 'we're not anywhere near that'. But Rae said 'I can't do it any more. I'm so tired'. She didn't want to die, bloodied and exhausted, on a battlefield. She wanted peace. She found it in palliative care—refused further treatment and died in days, in late April.

The lungs are of equal importance to the heart—they absorb oxygen from the air, and without oxygen none of our organs can function; most of all, the brain, which will die if deprived of oxygen for more than about four minutes. The

principal symptom of chronic respiratory failure is breathlessness, which generally gets slowly worse. None of us with normal lung function are even usually aware that we are breathing—it just happens naturally and quietly. But when we become aware of a difficulty in breathing, this is one of the most frightening physical symptoms and that fear can cause huge psychological distress. Although we can measure abnormalities of respiration (that is, blood levels of oxygen and carbon dioxide, and depth and rate of breathing), we cannot measure breathlessness, which additionally comprises this psychological component of breathing. Combine that breathlessness with a severe and unrelenting cough, and you have severe distress—again, that is quite likely to continue for many months or years, without a predictable outcome but often ending with a superimposed acute infection.

In the same way, doctors cannot measure pain. Nor can we measure the fatigue that accompanies severe breathlessness, or the existential component of restricted mobility, dependence on others, and the sense of being a burden that may follow.

The nervous system comprises the brain and the spinal cord, and the peripheral nerves that both collect sensory information and distribute messages to our joints, muscles, organs and skin. Acute damage to the brain can immediately be fatal (through trauma, a stroke or haemorrhage), but, if survived, can lead to a permanent, non-progressive disability. A profound stroke will cause permanent paralysis, often with loss of communication skills, and immobility and institutionalisation, and these circumstances may continue unchanged for years. An advanced incurable illness? Certainly. And associated with unbearable and enduring suffering? Certainly, for many people.

Neuropsychology professor John Bradshaw of Monash University has a deep understanding of the brain’s function.

His wife sustained a massive stroke in October 2011 at the age of sixty-five. She survived, but rehabilitation was ineffective and she suffered further strokes. He told the following story to Robyn Williams on the *Ockham's Razor* program on Radio National on 12 May 2013:

> The last again occurred during the night hours with facial convulsion and rapid loss of consciousness. As I followed the ambulance to hospital, I wondered whether this event was likely to prove terminal and, if so, whether it might be a blessed release for her from an unhappy existence. I knew that if the situations were to have been reversed, that is what I would have wanted for myself, and whatever the opponents of euthanasia would say, it is most certainly not the case that modern medical and hospice practices can promise a pain free existence of dignity and quiet surrender.
>
> We fear advancing age, yet dread the alternative, a premature demise. We seek the comfort and security of company, a partner for life or a part thereof, especially perhaps someone to share our declining years and save us from a lonely old age. Yet except in rare, possibly even fortunate, instances one or other of us will inevitably predecease he or she who is left behind and may thereby grieve the loss of a dear companion. The loss may occur relatively rapidly, as perhaps in earlier times, or nowadays it may be a more drawn out process as with dementia or stroke, with greater possibilities for medical intervention to delay the inevitable. The greater our life expectancy the more likely it will be that, paradoxically perhaps, the process of dying may itself become more lengthy and drawn out.

The time came when Bradshaw could not cope as her carer:

> I spent much time checking out eight such institutions (high care) which ranged from the splendid to the execrable. She has been there now for over a year and at nearly $50,000 per annum, plus medications (some very expensive) it is not clear what the future will hold when the money runs out.

Most profound-stroke patients have some degree of cognitive impairment, as in the above instance. It is hard to imagine a worse advanced incurable illness than a brainstem stroke. In this condition, all limbs are completely paralysed, the ability to speak and swallow is destroyed (tube feeding is necessary for survival), but spontaneous breathing remains, as does normal cognitive ability. It has

been described as a ‘locked-in state’; the sufferer is fully aware of their surroundings, but is completely unable to communicate except by movements of the eye. Harold, discussed in *A Good Death*, had such a stroke. This appalling condition is one for which even palliative care Professor Norelle Lickiss, an ardent opponent of assisted dying and a proponent of the damaged person’s responsibility to continue living in order to be able to trust others to care for her, declared that she would refuse care.

Acute injury to the spinal cord may cause permanent damage (quadriplegia), and is, tragically, most common in young, active people. Many of these people courageously overcome their disability, and are rehabilitated to be able to live productive lives, but some cannot achieve this, particularly if the quadriplegia is especially severe. They have an advanced incurable illness that is non-progressive and they can survive with intolerable suffering for years.

Christian Rossiter was in his forties when he had a fall that resulted in very severe cervical quadriplegia resulting in virtual total paralysis below the neck, a tracheostomy that prevented normal speech, and a PEG. He was totally dependent on carers for every single action: feeding, clothing, toileting, blowing his nose or scratching an itch. He was living in permanent care in an institution. This situation was never going to change—he had an advanced incurable illness due to chronic, permanent neurological organ failure. After eighteen months, he decided he had had enough suffering and requested cessation of his tube feeding. Given that Rossiter was competent, Chief Justice Martin of the Supreme Court of Western Australian granted his request, and stated that he had the same right to effective palliative care as any other patient who might be approaching death.

Exactly how Rossiter was palliated after cessation of his tube feeding is not known. He would have died of dehydration, a process taking seven to ten days, sometimes even longer, depending on how rigorous is the refusal of

fluids, and the vigour of the palliation of symptoms with sedatives. The principal symptom is thirst, but palliative care states that this can be negated by exquisite mouth care; pain from hunger is said to be minimal. It takes considerable courage to carry this out without strong support, and also reassurance that sedation to relieve any distress will be provided when the dying person requests it (not when the doctor thinks it is necessary—they are not the one who is suffering). The worst suffering must be the psychological kind: having to find the emotional strength to die in this way, while constantly wondering why society does not allow you to take medication that will put you to sleep peacefully in minutes, and die quickly and peacefully, instead of putting you through this macabre, prolonged ordeal.

Bill had an advanced incurable illness with similarities to Christian Rossiter's. (His wife, Carolyne, told his story in *The Saturday Paper*, 21 June 2014.) Bill also had a severe spinal injury, to the upper spine, and had only one functioning arm, but did not need tube feeding. He was having no treatment to refuse, until 2000, when both his kidneys were removed because of uncontrollable sepsis. He required dialysis three times a week, and suffered total renal failure in addition to spinal cord failure. He returned to work for two years, until he developed intolerable back pain due to the fracture of metal rods supporting his spine. His suffering was now intolerable and unrelievable. Unlike Christian Rossiter, he was not undergoing tube feeding, but he could refuse dialysis. This he did, and with compassionate palliation from his GP and a palliative care nurse, died peacefully at home in about a week without dialysis, due to excessive potassium in his blood (which Bill did everything to increase by altering his diet and refusing his medications). His family accepted his decision and shared his experience.

Equally distressing are slowly progressive paralytic neurological conditions, such as MND, MS and Parkinson's

disease, and many more less common but equally disabling conditions. Consider MND: progressive muscular paralysis with no curative treatment, which will inevitably be fatal in about five years, or less, from the time of diagnosis. That diagnosis is a death sentence, but it is the manner of dying that is so distressing. Ultimately the bulbar functions of the brain are affected, so voice communication is lost; as is, with the loss of hand function, even communication via an alphabet board. Swallowing is impaired, so that food and fluids may go into the airway rather than the gullet, causing an acute sense of choking—even saliva may become difficult to swallow, and the ability to cough up secretions, and inhaled food and fluids, is impaired. The fear of choking, and the actual sense of choking, is terrifying. And while all this is going on, the ability to breathe is diminishing, eventually to levels that can barely sustain life. None of these problems can be cured, and palliation is a euphemism in this situation. For swallowing problems, PEG tube feeding is offered, but this, while partially solving the problem of nutrition deprivation, prolongs the dying process. The same applies to breathing difficulties—respiratory support has some value but, again, prolongs the dying process.

MND does eventually reach a stage where death can be predicted within weeks or months but, even then, with the support of PEG feeding and artificial respiration, survival can be prolonged for years. The eminent scientist Stephen Hawking is evidence of this. He has had a form of MND for over fifteen years, and continues to survive with these means of support, because he has his brilliant mind to sustain him. He can still communicate via his computer, he can still make a contribution to society, he still has a purpose in living, but he has clearly stated that when he loses that capacity, he would welcome an assisted death. He said in a BBC interview (17 September 2013):

> I think those who have a terminal illness and are in great pain should have the right to choose to end their lives, and those who help them should be free from prosecution.
>
> There must be safeguards that the person concerned genuinely wants to end their life and are not being pressurized into it or have it done without their knowledge and consent as would have been the case with me.

Some neurological conditions progress more slowly but cause severe loss of function, and suffering without an end in sight. Those with such conditions do not have weeks or months to live—they may well have years, which makes their suffering even more difficult to bear.

Bron's story exemplifies this. She was a mother of three in late middle age, living in a modest suburban home with her unmarried, middle-aged son, who shared her care. When you entered her home in inner-eastern Melbourne for the first time, it was amazing to see in the front bedroom a massive mechanical device that looked appropriate for the dockyards. It reached from the floor to the ceiling, and across the ceiling until out of view. It was a mechanical hoist; not intended for goods or produce but for a human being.

However, during my visits to this home, I entered through the back garden and into a light-filled room, to greet Bron, sitting apparently comfortably, and smiling, in her well-appointed, electrically powered wheelchair. To all appearances, she was very content with life. I was not immediately aware that every morning, as had been the case for two years, she had been hoisted out of bed by two carers, then washed, toileted, dressed and fed by them, before being placed in her chair to face the day. In the evening, her son, on returning home from work, effectively reversed the cycle and put her to bed. When she went to sleep, her breathing was supported by a continuous positive airway pressure device.

That, in essence, was Bron's day. She had some devoted friends, who took her out regularly but with increasing

difficulty, transported in the back of her specially adapted van. She was becoming increasingly embarrassed at her inability to feed herself when eating out and to engage in communal activities. Her world was steadily shrinking. She spent all her time with limited mobility, and much of it in pain from her immobile joints, stiff muscles and unrelieved pressure points. Yet, you wouldn't know it because she seldom complained and her outward appearance was one of serenity.

What was Bron's problem? Inclusion body myositis. She had chronic, progressive muscular wasting and paralysis, first evident over sixteen years before, and steadily progressing from her legs to her arms, then to her breathing. Trouble with her legs led to falls, and the need for the wheelchair; trouble with her hands led to the need for assistance with personal tasks and feeding (but not swallowing), and trouble with breathing led to the need for respiratory assistance. She could not control her bladder and had a permanent catheter, exiting from her abdomen. But she was totally unimpaired in her ability to think and communicate. In some ways, her disease resembled a very slow form of MND, but without the bulbar aspects. Yet, it was equally relentless.

Bron was managing to stay in her secure and warm home environment, but only with an enormous amount of assistance from a devoted team of carers—professionals, friends and family. Of these, her son bore the brunt, as his two sisters were married with families of their own. Bron was acutely aware of the burden and restriction she was placing on her son's life and hated the imposition. Recently, to provide 'respite' from this grinding process for everyone, she had spent three weeks in an excellent institution that cared for disabled people (that is, a nursing home, not a fashionable term these days). Although it was a very good place, and although the care was diligent, Bron was shattered by the experience. She could clearly see herself in

the future, when this environment would be her only option, but when would this be? Perhaps it is not surprising that she sought a solution.

So, she discussed her end of life with her local doctor. He recognised her dilemma, and would support her in refusal of treatment and sign a death certificate if she died but, as a practising Christian, would not actively assist her. She had chronic organ (neurological) failure and an advanced incurable illness, but was not terminally ill, or predictably dying. Where to go from there?

Bron gathered her family around her and explained that she could go no further. She had a completed life, and had been ready to die for a while. Now she had reached her time to die. Her family understood and reluctantly supported her. She took oral medication and died peacefully in the company of friends.

One close friend who was present when she died wrote to me as follows:

> Earlier in the year you brought so much comfort to my friend Bron. She valued your visits and that you listened to her and gave credence to what she said. You saw beyond the image she projected from her wheelchair. Thank you for all you gave her at a time when she was so desperate.

Many people would not think of the bowel as a vital organ, yet it is, because without a fully functional digestive system, we will either starve or develop absorptive deficiencies that severely challenge good health. The bowel also has an excretory function for waste products, which, if deficient, produces faecal incontinence—a fundamental challenge to dignity. Disturbances of bowel function produce constipation or diarrhea, or a fluctuation of both, often with colicky pain from bowel distension, over-activity or obstruction. While these problems are often manageable, they may represent a chronic form of organ failure that drastically challenges quality of life.

Greta's story is an example of this. In her sixties, she phoned me in December 2015 after seeing me on *Q&A.* She was one of about forty desperate people who did this in the six weeks following the show, with some calls from as far away as Queensland and Western Australia.

Greta had been married but now lived alone and had no family in Australia. Prior to 2001, she had been a successful small businesswoman, socially outgoing and gregarious. Nevertheless, from about 1991, she had experienced bowel problems, eventually diagnosed as colonic inertia and diverticulitis. She underwent total removal of the large bowel, with anastomosis of the small bowel to the rectum. Complications led to a second operation, in which many adhesions were found, the small bowel was damaged and more of it needed to be removed. Sepsis and prolonged hospitalisation, for six months, followed.

Greta began to experience frequent abdominal intestinal pain, and explosive, uncontrollable bowel actions that wrecked her life. Ultimately, she agreed to an ileostomy (the creation on the abdomen of an opening—or stoma—of the small bowel, with a bag being used to collect faecal discharge). Severe adhesions were found to account for her pain, and such adhesions often cause recurring bowel obstruction. Greta had frequent episodes of bowel colic, requiring injections of pethidine, and hospital admissions. Expert opinion advised against any further surgical procedure, a pain specialist commenting that further abdominal surgery would be like 'entering a minefield'. Her frequent intubations and prolonged ICU care had led to a chronic chest infection with continual need for antibiotics. She persistently sought advice from pain specialists, but little other than regular opioids, with attendant side effects, could be offered.

Due to shortage of bowel, Greta's abdominal stoma was difficult to manage, and she suffered from frequent and unpredictable leaks from her bag, making it extremely

difficult for her to have any sort of social life, for fear of, and due to actual, highly embarrassing accidents. She had been on antidepressant and anti-anxiety medications since 2002, with marginal benefit. A frank assessment by her surgeon and her pain specialist in 2013 was that her situation could not be improved, and was likely to get worse over time.

After having a severe bowel obstruction, in 2015, she said that she 'hit the wall', and determined that she could not go on. In 2016, she had a psychiatric assessment, specifically to address her growing desire to end her life. This very careful examination found that 'she was at ease with her decision, and that her current medical condition makes her life intolerable'. The psychiatrist concluded that:

> There were no signs of impaired reality testing or judgment, although her thinking in this matter was clearly clouded by her pain and somatic concerns. There were no signs of a somatic illness. I would not describe her as depressed. I certainly did not find any signs of impaired reality testing or judgment that would detract from her capacity to make an informed decision about her own care needs. In short, I could not see any reason on psychiatric grounds to say that she is not able to make medical decisions, based on her own values and interests. She would not meet the criteria for involuntary treatment under the Mental Health Act.

In case you think Greta's is an exceptional case, I had a call three months later, after appearing on *Australian Story,* from a 55-year-old man from interstate who had had twelve operations for Crohn's disease over twenty-five years. He was suffering from almost identical chronic pain to Greta's, and had had advice and treatment from seven pain specialists, without success. After a recent visit to Melbourne for a trial of complex pain management, which failed, 'George' wrote, 'I am left with all the pain and no life. All I want out of this nightmare is to have some sort of life. Why should I have to live like this?' He, too, was contemplating ending his life. He could not work, had lost his sexual function, and was constantly on opioids but remained in daily pain.

These are both examples of chronic uncontrollable pain of somatic abdominal origin. They are reminiscent of the chronic pain from subacute bowel obstruction that caused Nancy Crick to end her life, in a blaze of publicity created by Philip Nitschke, in 2001. People like Nancy Crick, who are prepared to expose their suffering to the world, are very uncommon—they have enough to deal with without exposure to a ravenous media—but their stories are not as uncommon as you might imagine.

These are examples of *advanced incurable illness sufferers*, the name I give to a complex group of people who don't have a terminal illness but are suffering in a way not dissimilar to that of some people dying of cancer. However, it does not last for weeks or months, but for years—fifteen in Greta's case and twenty-five in George's—and their pain defies effective medical treatment. Chronic somatic pain is one of the commonest medical maladies, and one of the most ineffectively treated. It can lead to drug dependence, adjustment disorder (with anxiety and depression), loss of employment, loss of sexual function, relationship breakdown and violent suicide. While every effort, and then more, should be made to overcome such problems, if they are insuperable their bearers should not be ignored; they should be treated with respect equal to those experiencing similar suffering who are dying. People should not have to die with unbearable pain. Why should they have to live with unbearable pain?

When I first began to categorise 'advanced incurable illness', I recognised from my counselling of people with heart and respiratory failure, and people with neurological diseases, that they were having 'chronic organ failure', but I placed the group with severe physical pain in a separate category. Again, it dawned on me that the majority of this group are suffering from incurable conditions of the musculoskeletal system, another organ system that is vital

to human welfare even if its dysfunction is not usually life threatening.

Probably more common than Greta's chronic abdominal pain is back or spinal pain. Despite the vastly improved diagnosis of spinal pain, due to CT and MRI scans, many cases of severe pain continue without accurate diagnosis, particularly after multiple failed back surgeries. Myriad treatments, from facet blocks, and ketamine infusions, to intraspinal opioid pumps and spinal cord stimulators, are used, with variable results.

Norman's story started fourteen years ago. A successful professional and a performer, he developed sudden acute lower back pain and sciatica. He had a laminectomy, which made his pain worse. Some months later he had a spinal fusion but, again, his pain was not relieved.

He has been advised that there are no surgical options left. He has tried all forms of pain relief, including spinal injections, radio-frequency nerve blocks and an intraspinal nerve stimulator. He is on Lyrica and Endep for his neuropathic pain, and takes some opioids but they have little effect. He has been depressed since his failed spinal fusion, and has been on many different antidepressants. He has lost his job, his artistic solace, and his libido and sexual function. His wife is still supportive, but Norman is reaching a point where he cannot go on any longer. She understands that.

There are many variations on this theme. Any damaged joint may be the source of chronic intolerable pain. Problems with the larger weight-bearing joints (such as the hip and knee) are more common, and with joint replacements much of this pain can be relieved—but not always. The spinal joints cannot be replaced, only fused, in an, often desperate, attempt to relieve pain whose actual source is uncertain. As a result, the outcome is often tragic.

In the more recent years of my urology practice, I have provided many reports to Victorian Workcover and the

Transport Accident Commission, regarding the long-term urological effects of spinal injuries. Mostly the effects are the result of failed, often multiple, attempts at treatment. Sufferers are often manual workers, relatively young, whose injuries result in them being unable to work, cause serious adjustment disorders (with depression and anxiety) and have a disastrous effect on their social and sexual relationships (often including erectile dysfunction), and some of these sufferers become suicidal. Chronic unrelievable pain can do that.

I have described the effects of unrelievable pain coming from one major joint. Imagine having unrelievable pain from almost every joint in your body, as with a polyarthritis such as rheumatoid arthritis. I counselled one woman who had suffered rheumatoid arthritis for thirty years, and had had more than twenty joint reconstruction or replacement operations, from her knees to the small joints of her fingers. Rheumatoid arthritis is not only a multi-joint disease but an autoimmune disease that has subtle effects on more than simply the joints. She told me she could not battle on any longer—her strength and ability to continue were gone. She may have been in a depressed mood as a result of her circumstances, but it was entirely appropriate—there was nothing more that modern medicine could offer her. She had run her race, and was ready to die. I helped her.

I counselled someone else who had arthritis in almost every joint in her body. Her treating rheumatologist had used every possible technique to relieve her pain, but had at last run out of options, reaching a point of medical futility. When I visited the sufferer at her home, she was curled up in bed. Every single movement she made was excruciatingly painful. She could go no further. She sought my help, and I gave it to her. As I did so, I reflected on the fate of British rheumatologist Nigel Cox, who was convicted of attempted murder in similar circumstances.

Our musculoskeletal system is fundamental to our existence. We take for granted the ability to move about, walk and run freely, and without pain or hindrance. The loss of that ability is an existential loss, which creates a suffering as deep as any other loss. Certainly, in modern times people can overcome this disability, and they should never be judged inferior because of the loss they have experienced. Indeed, their ability to triumph over it should be admired, but that triumph does not obliterate the loss, and not all can make that leap of courage, or maintain it over many years in the face of gradual decline. Add unremitting pain and the problem is magnified.

Chronic musculoskeletal conditions, principally back pain and osteoarthritis, are the most common reason for chronic pain. It is a distressingly common problem: a study from 2012 found 26.9 per cent of the Australian population was affected (Christopher Williams, *The Conversation*, 23 November 2015).

Modern medicine is reasonably successful at dealing with acute pain, and with pain over the short term, as may be the case with terminal-cancer pain. However, chronic pain is a different matter. Opioids, and their derivatives and cousins, are effective for acute pain, but as pain increases or persists, tolerance develops and increasing doses are required. Quite apart from the problem of side effects from increasing doses, efficacy diminishes over time. These drugs are not recommended for the long-term treatment of chronic pain but what else is there? Not much. Antispasmodics, anticonvulsants, antidepressants and anti-inflammatories in various combinations, together with psychological counselling, can provide some help, but, in truth, medicine does not have the answer to chronic pain.

Medical research bears this out. Researcher Laura Hitchcock et al (*Journal of Pain and Symptom Management*, 1994) reported on the experience of chronic non-malignant pain. They cited the Nuprin Pain Report (1985), which found

that pain was reported as severe or unbearable by over one third of respondents with joint or back pain. A critical review of the literature concerning patients with chronic non-malignant pain affirmed a prevalence of depression substantially higher than in those without pain. Of patients with severe chronic non-malignant pain, 71 per cent reported that it interfered with their personal relationships, including marital relationships. A majority (69 per cent) reported feeling ‘hopeless’, and 50 per cent had considered suicide. Chronic pain, particularly back pain, is a serious matter, and can be life threatening.

So, I have come to see severe chronic musculoskeletal pain as another form of chronic organ failure. Its significant difference from chronic heart or respiratory failure is that, in most circumstances, it does not have the remotest connection to terminal illness, unless, as can happen, these sufferers are driven to violent suicide by their pain. It is also clear that advanced incurable illness is synonymous with chronic organ failure in this broad sense, and that for people with chronic unrelievable pain, organ failure is usually a cause.

Evidence provided by the Victorian coroner to the Victorian Parliamentary Inquiry (Legal and Social Issues Committee) in 2016 revealed that, between 2009 and 2014, of 240 violent suicides by people with serious physical health problems, at least 60 per cent were people with an advanced incurable illness.

In 2015, the Australian Commission on Safety and Quality in Health Care issued a national consensus statement titled *Essential elements for safe and high-quality end-of-life care.* It defined end of life as:

> The period when a patient is living with, and impaired by, a fatal condition, *even if the trajectory is ambiguous or unknown* [my emphasis] … This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma … People

are ‘approaching the end of life’ when they are likely to die within the next 12 months.

This is not a statement on suffering but it recognises that patients with chronic and malignant diseases may have intolerable suffering even though their trajectory to death is ambiguous or unknown. It is a clear indication that fatal conditions, such as major organ failure, may have unknown or unpredictable trajectories, and that end-of-life care should not be confined to the terminal phase of a terminal illness, when the dying trajectory is obvious.

Does this make the suffering of such people any less significant or any less worthy of consideration than that of those who are terminally ill? I don’t believe so, because suffering is not just pain, and it is not confined to the terminally ill.

5

SUFFERING

What is suffering? Perhaps the most graphic example of suffering for us in the western world is that of Jesus Christ. The Christian message is that he suffered so that we might be saved. His physical suffering is almost palpable in the descriptions of his death in the Gospels, and in the representations of his death in the visual arts, and as heard in sacred music of extraordinary pathos and beauty.

Christ's physical suffering is self-evident. His crown of thorns, his being scourged, his forced carriage of the cross to Calvary, his nailing to the cross, and subsequent slow dehydration and organ failure, are there for all to see, and imagine. Can anyone doubt his psychological suffering as he was denied by his followers, mocked by the crowd, humiliated by his captors, and, almost certainly, in great terror of his slow, painful demise? His existential suffering is summed up in his cry 'My God, my God, why hast thou abandoned me?', before he died suddenly and mysteriously

in six hours, according to the Scriptures, rather than the usual three to four days.

Even non-Christians can imagine Christ's suffering, have sympathy for him, and attempt to feel his distress—to have empathy. Sympathy means to feel sorrow for such suffering, whereas empathy involves the ability to understand and share the feelings of another person. Not all human suffering is as dramatic and evident. Often, it is hidden by non-complaining dying people, who seem resigned to their fate, not imagining that they can have any influence over the outcome.

It is clear that suffering in the health domain has three separate threads, which nevertheless usually merge into one another and that none is likely to be present without at least one of the others. These are physical, psychological and existential suffering.

Physical pain is the predominant type of physical suffering for most people. When we bash our thumb with a hammer, we feel instant pain and it has no more context than the immediate distress, unless you are a concert pianist preparing to perform Ravel's 'Piano Concerto for the Left Hand' later that day. The context of pain is all important, and illustrates that, although the pain is immediately felt in the thumb, it is processed in the brain, perceived by the brain, and can be either magnified or diminished according to various perspectives. One person might see it as a huge disaster; another as an excuse to have a week off work. Some people may grow from the experience of pain, others may be crushed by it. A mother may be able to endure the pain of childbirth because its outcome is so profound and full of hope for the future, but that same woman dying painfully of breast cancer will be unlikely to find hope and value in this different pain. That same mother, perhaps with two young children and a husband whom she loves dearly, will be devastated by such circumstances, and her pain will be of a different kind to that of someone aged ninety with a

similar condition who is nearing the end of their natural life. So, pain has a very personal component; the apparent ‘same’ pain will have a very different meaning to, and impact on, different people. We cannot, and should not, judge anyone’s response to pain, if for no other reason than that we cannot measure pain.

When I, as a doctor, see your swollen, bruised thumb, consequent upon the hammer attack, I can imagine, perceive, believe that there is pain, but I cannot measure that pain. It exists only in your mind. I have to ask you, on a scale of pain, for your assessment. As Australian author Hal Porter observed in his memoir *The Paper Chase*, ‘To someone else, however sympathetic, however imaginative, my pain is as ungraspable as the salt in water’. Your psychological or emotional state will have a very big influence on how you feel your pain, which is why treatment directed to altering the psychic state can alter the perception of pain, and therefore the intensity of pain. Thus, a person who experiences a new pain, and fears that it might be due to cancer, can find that the pain improves when a logical explanation for it is provided and the possibility of cancer eliminated.

I first saw someone experiencing acute breathlessness in the Melbourne University Regiment sergeants’ mess, when a colleague had an acute asthma attack as we were sharing a beer. It was an appalling experience to watch, helplessly, my friend struggling for life, as it seemed to me. What must it have been like for him, scared to death that his next breath might be his last? Breathlessness is one of the commonest symptoms experienced by dying people, but is virtually universal in chronic heart and respiratory disease, and some neurological diseases such as MND. A woman whose husband died of lung cancer wrote to me, ‘The oncology staff were marvellous and did all they could to ease Peter’s final days. However it was a dying process that we both wished he had not undergone. It was horrible to watch him

struggling for breath, in pain, often nauseated, and in considerable distress'.

Breathlessness, like pain, is not measurable. It can be observed—the levels of oxygen and carbon dioxide in the blood can be measured, and the movement of air in and out of the lungs determined—but the essence of breathlessness is a sensation, a perception, bound up with fear. It quintessentially encompasses the concept of distress, as opposed to pain; again, the unmeasurable component of physical symptoms that exists in the psyche. Dr David Fishbein and others, writing in the *Journal of Pain and Symptom Management* (1989), reported that 'the prospects for such [cancer] patients are bleak and frequently their dyspnoea [breathlessness] persists unabated until their demise', while Dr Martin Cohen (*Cancer Investigation*, 1992) reported that 'Dyspnoea is probably an even more distressing symptom than severe pain'. While it may occur alone, breathlessness is often accompanied by severe, or even relentless, coughing, and/or pleuritic pain (chest pain upon breathing or coughing), which can make every breath or cough a terrifying anticipated experience.

Palliative care physician Neil MacDonald might argue with Cohen's observation. He stated (*Journal of Pain and Symptom Management*, 1995) that 'weight loss, asthenia and anorexia [loss of appetite], often associated with chronic nausea, are among the most common symptoms afflicting patients with advanced cancer ... family studies demonstrate that ... this complex ranks at the top of physical causes of suffering and causes psycho-social distress. The syndrome devastates family relations, and makes the patient dependent on the family and healthcare institutions'. MacDonald was describing cachexia, a very common accompaniment of cancer, which is also known as 'the wasting disease' because of the slow disintegration of the body as the cancer cannibalises its metabolism. This is one of the most important reasons why many people with

cancer cannot die at home. The process takes so long and requires so many resources that it demands too much of those the patient lives with.

But physical pain, breathlessness and cachexia, although very common, are not, for a moment, the end of the physical symptoms of suffering the dying patient experiences. The digestive system is a deep well of problems. Imagine being unable to swallow your food, due to an oesophageal blockage; to enjoy your favourite dish or preferred drink, for fear that it will spill into your breathing tube, and cause a bout of coughing and the fear of choking to death; or not even being able to swallow your own saliva, and having to repeatedly spit it out into a tissue. Your dilemma? Continue as you are and slowly starve, or, more quickly, dehydrate, to death, or accept a PEG, with the consequent prolongation of dying, with perhaps even more distressing symptoms. There are nausea and vomiting, sometimes temporary and intermittent, as with chemotherapy, or persistent, as with many abdominal cancers. There is persistent diarrhoea, perhaps alternating with constipation, or the persistent constipation and abdominal pain associated with palliative opioids. Not to mention faecal incontinence, a threat to dignity that swamps all the above, as does urinary incontinence. Some advanced cancers can result in untreatable ulcers, which are associated with discharge, bleeding and odour. This condition sociologist Julia Lawton describes as ‘the unbounded body’, and puts the sufferer in an embarrassing and socially isolating state.

These symptoms impose suffering that is a physical burden, but much, and equivalent, suffering is more due to a loss: for example, profound paralysis, or loss of sight, hearing or speech. These functions are central to living a good life, and are essentially about communication and pleasure. Their loss may have no association with physical pain but are associated with huge psychic pain. There is no doubt some people bravely overcome such disabilities, if

acquired early, and live long, productive lives, but when such problems occur towards the end of life, and the resilience needed to overcome such burdens may be gone, it is different. What might once have been tolerable and surmountable may later on be intolerable and crushing.

The impact of hearing loss on a musician, loss of sight on an artist, or loss of voice on a singer can be readily imagined. Incisive commentator Christopher Hitchens described in *Vanity Fair* magazine his reaction to losing his voice, due to treatment of laryngeal cancer in 2011 ('Unspoken Truths', 9 May 2011):

> Like health itself the loss of such a thing can't be imagined until it occurs … Deprivation of the ability to speak is more like an attack of impotence or the amputation of part of the personality … To lose this ability is to be deprived of an entire range of faculty; it is assuredly to die more than a little. My chief consolation in this year of living dyingly has been the presence of friends. I can't eat or drink for pleasure any more, so when they offer to come it's only for the blessed chance to talk … And what do I want back? In the most beautiful apposition of two of the simplest words in our language: the freedom of speech.

Belgian twin brothers, born with congenital deafness, lived closely together, communicating by sign language, and working side by side as cobblers. As they reached their forties, an associated congenital defect was leading to them becoming blind, and with this, the loss of sign language, and complete disengagement from each other and the world; they were condemned to solitary confinement in a soundless and sightless world for the rest of their lives. Yet, some were cruel enough to criticise their decision to end their lives together, and to criticise those who assisted them!

Possibly the greatest loss of all is that of cognition—the power to think, express emotions and ideas, and to communicate—as happens in progressive dementia. This is particularly distressing in the early stages, when sufferers are still able to see, feel and understand what is happening.

No wonder extreme anxiety, depression and psychosis often accompany this dreadful affliction.

The physical suffering I have described does not, of course, occur in a vacuum; it is afflicting a thinking person, who has emotions and relationships. While profound psychological suffering may accompany physical disease, it is usually not visible, as most people hide such distress for the sake of those around them. Nevertheless, it is not hard to imagine feeling fear of what is to come in a terminal illness, or feeling the already experienced distress of a chronic illness, which may be seen as stretching unremittingly into the future. However much you try to console a person in such a situation, words alone may be of little benefit. While kindness and caring are a wonderful help, the anxiety, fear, and even terror, may persist.

A depressed mood will usually descend in such circumstances, but this is not a clinical depression. It is a natural human response to the appalling circumstances being faced—an adjustment disorder with features of anxiety and depression is the official psychiatric description—and is often resistant to any medication. Unless the circumstances can be changed, the mood will persist. It is an exceptional person who goes cheerfully to their death, unless they see it as a merciful release from intolerable suffering. Usually such a person has had a full life, a completed life, and is ready to die.

Palliative care physicians are often surprised to find that physical symptoms, particularly pain, are not the usual reason for assisted dying requests, and that such requests continue despite pain control. RJ Kohlwes (*Archives of Internal Medicine*, 2001) acknowledged this when he wrote:

> It is not necessarily physical distress that motivates desire to hasten death. Rather the psychological and existential dimensions of suffering—which are, perhaps, no less central in determining quality of life—also emerge as important reasons behind patient requests for physician assisted death.

It is suffering of an existential kind that dominates; it involves losses of immeasurable elements that contribute to our *existence* as human beings. United States lawyer and bioethicist Ben Rich in his article 'Pathologizing suffering and the pursuit of a peaceful death' (*Cambridge Quarterly of Healthcare Ethics*, 2014) has described existential suffering as 'the experience of agony or distress that results from living in an unbearable state of existence including, for example, death anxiety, isolation and loss of control'. Dying cancer patient Ron Player wrote in *The Age* (13 June 2016):

> I am 84 and in palliative care at a fairly advanced stage of terminal lung cancer. It seems none of the letters to *The Age* deal with the kind of ordeal I am experiencing as I wait to find out how long I have to wait to die. The care here is great and any physical pain is being effectively held at bay for now. What I find most difficult is the mental pain: the anticipation of a perhaps unbearably slow decline to my eventual outcome. The thoughts that imagination conjures run wild. This, for me, is what assisted suicide would address. The present prolonged uncertainty is very cruel. Once death is all that awaits one, the sooner the better.

Loneliness is very significant for many elderly people who have lost their spouse and are living alone, frail and in fear of being incarcerated in an institution when someone else determines that they can no longer look after themselves. It was mentioned in the vast majority of counselling requests from the frail aged that I've received and is usually accompanied by a depressed mood that is very difficult to treat. A change of circumstances will often help, but not usually an unchosen removal from home to an institution.

Some describe these as spiritual losses; to others, they are losses in the social realm. American anthropologist Frances Norwood learned Dutch and lived in the Netherlands for three years, immersing herself in the community of dying people and their doctors. Describing her experiences in a wonderful book *The Maintenance of Life*, she coined the term 'social death' to describe these losses, which were often associated with the modern, slow, process of dying.

She writes: ‘there is something about a person that can die prior to the death of the body. Social death cannot be attributed to a single point in time nor to a strict set of behaviours. It is a series of losses—lost identity and lost ability to participate in social activities and relationships—that eventually culminates in a perceived disconnection from social life’.

Norwood described loss of meaning to, and purpose in, life, loss of control, loss of social engagement and loss of spirit, as critical losses, and to these I would add loss of any enjoyment in life, and the sense of being a burden. She found ‘there is simply something about a person’s spirit or essence that sometimes dies before their bodies do’. To me, she is describing how they have reached their time to die before they reach their natural death—this is social death. In that circumstance, ‘patients make the decision to alter the exit time of biological death to have it coincide more closely with social death’. Norwood explains that dying is now often prolonged, and marked by long periods of decline and social losses.

These losses are complex and indefinable, but they all relate to our fundamental existence as human beings, hence the term ‘existential suffering’. As might be imagined, they are most difficult, if not impossible, to palliate.

These existential losses are at the very core of end-of-life suffering. They do not, of course, occur in isolation but are intrinsically related to physical suffering and physical losses, and exacerbated by the psychological milieu in which all this is taking place. In the absence of any physical illness, existential loss can occur due to psychiatric illness. Thus, suffering is an amalgam of phenomena, much of which cannot be seen or measured, but that other people, with understanding and empathy, can imagine. And the effects are cumulative. A pain that might be tolerable if believed to be temporary will be intolerable if seen as likely to continue and get worse; and a similar pain that could be bearable

with anticipation of recovery will be far worse if experienced when someone is anxious, depressed and feeling out of control, knowing that they are not going to survive.

From its earliest days, palliative care recognised this complexity, with Cicely Saunders coining the term ‘total pain syndrome’: an amalgam of all these distresses, involving an understanding of the immensity of suffering. Despite this early recognition, palliative care’s emphasis has always been on physical suffering, particularly pain, as the symptom most amenable to relief. It was not until the early 2000s that much exploration of existential suffering occurred, and it was the realm of sociologists, rather than doctors. Professor of sociology Kathy Charmaz described the ‘loss of self’ as a fundamental form of suffering for the chronically ill. She wrote (S*ocial Health and Illness*, 1983):

> Physical pain, psychological distress and the deleterious effects of medical procedures all cause the chronically ill to suffer as they experience their illnesses. However, a narrow medicalised view of suffering, solely defined as physical discomfort, ignores or minimises the broader significance of the suffering experienced by debilitated chronically ill adults. A fundamental form of that suffering is the loss of self in chronically ill persons who observed their former self image is crumbling away without the simultaneous development of equally valued new ones. As a result of their illness these individuals suffer from (1) leading restricted lives, (2) experiencing social isolation, (3) being discredited and (4) burdening others.

Palliative care professor Michael Ashby (*Medical Journal of Australia*, 1995) summed up these existential aspects when he wrote, ‘For many people who are dying, it is not just a question of comfort or absence of physical suffering (framed in the negative) but a loss of function, independence and role which are the hardest to bear’.

My introduction to the concept of suffering in a medical context came from reading an article by Dr Eric Cassell, ‘Diagnosing Suffering: A Perspective’ (*Annals of Internal Medicine*, 1999). He stated that, ‘Current treatments keep people alive long enough to enter the chronic, terminal

phase of their illness; the duration and severity of their suffering is thereby increased'. He defined suffering as 'a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted', and added 'Suffering is an affliction of the person, not the body … When physicians attend to the body rather than the person, they fail to diagnose suffering … Fear of the future contributes to suffering'. He wisely observed that 'Suffering is not suspected unless the patient makes its presence clear' and 'The diagnosis of suffering is therefore often missed, even in severe illness, and even when it stares physicians in the face'.

Remember Rudi Dobron? He certainly made the presence of his suffering clear, and I would have thought it was staring Caritas Christi palliative care in the face. Their response has three possible explanations: they did not see it, they underestimated it or they wilfully ignored it. In any case, there is no excuse for such lacks in care.

Palliative care physician Natasha Michael, writing in *The Age* (27 November 2015), acknowledged Eric Cassell's contribution to the recognition of suffering. Then she stated, 'As current law regarding right to life stands, both patients and doctors enjoy equal protection. The directive of "do no harm" protects the patient's right to life in circumstances when a doctor could be tempted or even coerced to end it'.

Michael's contention that patients and doctors enjoy equal protection under the law regarding 'right to life' is bizarre. The only right patients have under statute law is the right to refuse treatment (sometimes only for a current condition), and this varies from state to state in Australia. They can appoint an agent (or surrogate decision-maker) in most states. However, they may have no treatment to refuse. As well, they cannot request any particular treatment —decisions regarding treatment, including end-of-life palliation, remain strictly the prerogative of the doctor. Doctors may or may not accede to requests for increased

palliation or assistance in hastening death. Doctors control the use of drugs, the doses of drugs and how often they are given, and there is ample evidence that these decisions depend on the doctor's values and perspectives.

In his article 'Imbalance of power between patients and doctors' (*British Medical Journal*, 2014), professor of epidemiology and public health Christian Koeck confirmed that sickness and the inevitability of death trigger fears of loss of control and power, and noted that patients yield power to physicians because one party has knowledge and the other is apparently ignorant. He stated that 'communication often tends to run from provider to patient. As a result the disease is isolated from the patient'. Therefore, 'The information patients could provide is ignored, devalued, and not used in the search for treatments appropriate to that patient'. Having confirmed Cassell's point, Koeck closes with 'doctors can provide only help, not salvation', a timely reminder to religious-based palliative care of its limits.

Dr Michael has fallen back on the traditional medical ethic of 'do no harm', which regards hastening death as causing harm, a notion dating from Hippocratic times. It stems from the notion that death is 'bad', when in fact it may be desired by the patient and seen as 'a blessing' or 'release', as palliative care physician Roger Hunt notes (*Palliative Medicine*, 1998). The *British Medical Journal* 2014 editorial 'Death can be our friend', by Murray Enkin, Alejandro Jadad and Richard Smith, clearly challenges the direction of modern medicine in its attitude to death, and, to me, acknowledges that there is a 'time to die'. Medicine is changing; the views of patients are now being considered. Is it not a grave harm to allow a dying patient's suffering to continue, particularly if that patient requests that it be relieved, even if such action hastens death? Who is to judge the harm? Yet we are still witnessing conflict between the paternalism of the medical profession and the autonomy of

patients. Lesley Cowie clearly expresses this in a letter to *The Age* (13 June 2016):

> Dr Katrina Haller [CEO of Palliative Care Victoria] argues that it is the first duty of a doctor to 'do no harm'. Does she really believe that allowing those persons who gain insufficient or no relief from medications to die a drawn-out agonizing death, against their wishes, is doing no harm? The greater harm is to remove the power of choice from the dying, and to condemn them to the kind of death others have chosen for them.

It is clear that suffering is highly subjective, is immeasurable, and therefore difficult to quantify or define for legal purposes. However, it is at the heart of requests for assisted dying. In relation to such requests it is not the role of the doctor to judge whether there is sufficient suffering to comply with a request; it is simply to determine that the circumstances exist for there to be intolerable suffering and to ensure that the request is rational. If the doctor is uncertain, then a psychiatric assessment, to check for irrational thinking, is appropriate.

Palliative care is dedicated to the relief of suffering. How well does it succeed?

6

PALLIATIVE CARE

Palliative care is one of the most important developments in modern medicine. It aims to provide compassionate and holistic care for the terminally ill. Palliative care developed in the 1960s, in the United Kingdom, in response to the increasing power of modern medicine to extend life and prolong dying, and dying was moved from people's homes to hospitals and other institutions, such as nursing homes. Aiming to provide compassionate and holistic care for the terminally ill, its stated aims are the prevention and relief of suffering, improvement in quality of life, and respect for patient autonomy (or patient self-determination) in treatment options. It was a very welcome development and one of the most important changes to medicine in the past fifty years. Its growth has been incredible; a testament to the need for such care. From its humble origins in a single London hospice, it has grown into a worldwide organisation, formally practised in almost all western countries, with national and international scientific meetings, professional

associations, rules and regulations, published guidelines and protocols, and the rigidities of practice that accompany such growth. Specialist medical registration has been established, and a section created within the Royal Australasian College of Physicians (RACP). To establish the acceptance of palliative care, much research has been carried out.

The term ‘palliative care’ was first coined by Canadian doctor, surgeon and academic Balfour Mount in 1974, as an alternative to ‘hospice’. This was the original name that Cicely Saunders (initially a social worker, then a nurse and finally a doctor) gave to it when she established the first modern hospice, St Christopher’s in London, in 1967. The word ‘hospice’, of course, has connections to religious houses of rest and succour for travellers in the middle ages.

Palliative care is an amalgam of medical and nursing components. The doctors are the palliative care physicians and control palliative medicine (a distinct medical speciality). There are at most 400 members of the Australian and New Zealand Society of Palliative Medicine but this small group has a profound influence on the provision of care to the dying. The nursing profession is also particularly influential in palliative care, because it provides the bulk of the care, and the day-to-day, hour-by-hour attention to the problems, of the dying. Social workers are other significant contributors to this holistic care, as are those who practise in the areas of psychic health and spirituality.

Palliative care has gained government support and funding such that its position as leader and adviser in the care of the dying is unchallenged. There is no doubt in my mind, or that of governments, that palliative care provides significant benefits to the community. Governments repeatedly tell the public that palliative care is all that is needed for adequate care of the dying. The Australian Medical Association (AMA) concurs that more palliative care is all we need.

Palliative care organisations, of course, do nothing to disturb this image, and the public remains largely unaware of the realities of referral to their services. Moreover, there is a veil of silence over treatment outcomes. Palliative expert Vittorio Ventafridda et al wrote in *Palliative Care* in 1990 that ‘the lack of control of physical suffering among cancer patients in the last days and hours of life is a common medical problem, but it is rarely discussed in an open fashion’. Nothing has changed since then, and only rarely do stories emerge of the unsatisfactory management of some end-of-life suffering.

Palliative care specialist Derek Doyle, of St Columba’s Hospice, wrote in the foreword to the book *Palliative Care Ethics,* ‘It is often said that a metaphorical halo shines over specialist palliative care and its practitioners with the result that some of its claims and assumptions have gone unchallenged by all but a few’. The inherent ‘goodness’ of the enterprise, and the essentially closed nature of palliative care, has allowed its rhetoric to escape examination as it glows under a mantle of political correctness. The gap between the rhetoric and the reality of palliative care needs to be examined.

In January 2015, I was excited when the organising committee for the annual conference of RACP invited me to deliver a plenary address on the general topic of end of life. My subject was to be a critique of palliative care, which the committee accepted. However, when fellows of the college learned of my invitation, and the subject of my address, a substantial number of them apparently (numbers and/or names were not disclosed) made complaints to the college board, and my invitation to speak was withdrawn. Many senior fellows were appalled at this academic censorship, in the spirit of the quote attributed to Voltaire ‘I disapprove of what you say, but I will defend to the death your right to say it’, and they said so loudly and publicly, but to no avail. They, reasonably, assumed that it was the palliative

medicine coterie who had complained. It seems, though, that Derek Doyle's followers wanted to keep the halo intact!

This chapter is largely based on my planned address to RACP.

Due to the compassion and energy of Cicely Saunders, palliative care has grown from one London hospice to be a specialty in the western world that has strong government support. However, only twenty-nine countries have achieved 'advanced integration' of their palliative care services with the wider health and social care system.

In order to establish palliative care as a specialist medical discipline, and more than just compassionate nursing and the use of morphine to relieve pain, at least twenty-seven journals are devoted to research into it. Careful examination of these journals reveals an intuitively obvious conclusion: that ethical research in this area is fraught by a constantly moving target, making accurate statistical analysis virtually impossible.

Statistical analysis depends on having two comparable populations with one variable (usually an assessment, investigation or treatment) whose effect is being measured. One population is a control group, which receives no intervention, to be compared with the group receiving treatment or assessment. But the clinical circumstances of dying patients do not stand still. Multiple biological functions are deteriorating, and new symptoms are emerging and increasing, often with a crescendo towards the end, while psychological and existential suffering is escalating. Further, it is ethically difficult to maintain control groups when disadvantage may accrue due to adherence to study criteria. At best, much palliative care research is fragile, and suggestive in nature rather than scientific. That there is a truly sound evidence base is arguable.

To make matters even more difficult, as Debra Rowett and David Currow (*Australian Prescriber*, 2014) recently stated:

> Patients receiving palliative care are at high risk of adverse effects from drugs. As these effects can be difficult to distinguish from the symptoms of the terminal illness, harm from medicines is often not recognised. Adverse effects contribute to the burden of symptoms at a time when good control of symptoms is paramount. Adding another drug to treat the adverse effects can compound the problem.

Imagine trying to assess the course of a disease when you cannot readily distinguish the effects of treatment from disease progression. Rowett and Currow's article effectively indicates that, even fifty years after the establishment of palliative care, a level of experimentation goes on in treating terminally ill patients. They wrote: 'prescribing medicines to relieve suffering and distress is the cornerstone of palliative care. However, there is limited evidence about the efficacy and safety of many drugs in palliative care. Currently most of this evidence comes from patients with cancer rather than those with other terminal chronic diseases'.

There is powerful confirmation from a Cochrane review (an international systematic review of primary research in human health care) of the effect of antidepressant drugs on adults with cancer. In three trials studying quality of life for such patients with depression, none showed any benefit from antidepressants—there was no significant difference between placebo and active treatment.

Despite the subjective impression that most patients benefit from their hospice care, it has been exceedingly difficult to demonstrate any objective benefits from such care. Palliative care and cancer specialist Camilla Zimmermann and others (*Journal of the American Medical Association,* 2008) studied the outcomes of palliative care, and concluded that 'there is scant evidence to support the effectiveness of specialized palliative care for patients with

terminal illness in terms of quality of life, patient and care giver satisfaction, or economic cost'. This study confirmed earlier results, but is subject to the same criticism I made earlier, that accurate study of palliative care is exceedingly difficult. As palliative care specialist Carlo Peruselli stated (*Journal of Pain and Symptom Management*, 1997), 'the complexity of assessing the impact of palliative care is far greater than in other fields of medicine due to the shortcomings of traditional outcome measures'. However, the sheer volume of research gives the specialty an appearance of scientific validity. In 2014, Jack de Groot, previous CEO of Caritas Australia, wrote in *The Age* that 'the truly compassionate response to our dying family members is the highest quality, evidence-based palliative care'. Unfortunately, the evidence base for it is not very strong.

Dr Peter Johnson, in the same newspaper, stated:

> No one working in the medical profession could sensibly deny that good well-resourced palliative care is a great advance. Sadly, even those who work in palliative care realise, however, the limits to the benefits some patients receive, leaving them distressed, in pain, or otherwise facing a miserable time, often shared by their loved ones, before their inevitable end.
>
> It's about time those who ignore the existence of such patients came up with a practical solution not couched in platitudes, philosophy or the solution that more funding might produce even better palliative care in the future. The simple acceptance of the fact that, sadly, for some there are worse things than dying would be a good start.

So, while I have no doubt at all that palliative care provides significant benefits to many people, that is not a scientifically verifiable contention.

Illustrative of the application of pseudo science is the list of scales for use in the assessment of dying people provided by doctor and philosopher Daniel Sulmasy (*The Gerontologist,* 2002). These templates include a pain scale, a meaning of life scale, a death-transcending scale, a religious coping measure and spirituality wellbeing

measure, a daily spiritual experience measure, and plans to develop a dignity scale and a hope scale.

We constantly hear of the tremendous advances in palliative care. Governments repeatedly say that there is no need to revise laws on assisted dying because palliative care deals very effectively with all the problems of the dying. What is the response of palliative care to this rhetoric? Only the confirmation that it deals very effectively with the terminal patient's pain. There is no public discussion of how this terminal pain, or other suffering, is relieved.

Careful examination of the literature reveals the extent of suffering in the terminally ill, and the difficulty in measuring and relieving it. In 1961 Cicely Saunders wrote in *Textbook of Pain*, 'We are now always able to control pain in terminal cancer patients sent to us and only very rarely indeed do we have to make them continually asleep in so doing'. This exaggerated focus on the successful relief of pain is contested by anaesthetist and pain specialist Professor Michael Cousins, who stated in 2010 that '10% of cancer pain was so difficult to treat at the end of life that some patients were given drugs to sedate them to unconsciousness, culminating in death over several days to a week'. Dr John Harrison, responding to a lay writer (*The Age*, 13 June 2016), wrote:

> [He] is seriously misinformed if he believes that 'extra morphine' will deal with severe cancer pain. Morphine, even when combined with other medication, does not always satisfactorily treat cancer pain and its consequences. Also the drugs may have unpleasant side effects, making the choice between pain and side-effects difficult. Euthanasia properly administered should be considered part of palliative care.

Pain specialists Norman Harden and Mitchell Cohen stated (*Journal of Pain and Symptom Management*, 2003) that 'neuropathic pain is largely resistant to treatment with commonly prescribed analgesics', while Professor Ashby noted in the *Journal of Law and Medicine* in 1995, 'We have

reached saturation point with what we can do with these drugs [opioids]. There are two or three pain syndromes which are particularly difficult to treat—nerve pain, bone pain, and pain that is largely in the psychological sphere'.

Further, breathlessness is exceedingly common, affecting as much as 70 per cent of terminally ill cancer patients, and often increases in severity as death approaches. Existing methods to relieve breathlessness still rely on opioids, which have the potential to hasten death. Similarly common are cachexia (wasting), immobility, dependence and anorexia, for which there are no palliatives except for good nursing, to try to make the sufferer's life less distressing. Nausea and vomiting can be minimised, but incontinence, ulceration, discharge and odour are not unusual, and exceedingly difficult to palliate, and all are an attack on dignity. Physician Daniel Johnson and others (*Journal of Pain and Symptom Management*, 2005) found that, despite the broadly acknowledged goal of effective symptom management, 'studies of terminally ill patients consistently demonstrated that pain and other symptoms such as dyspnoea, fatigue and depression remain highly prevalent in varied settings. Even in hospice and palliative care settings, where inter-disciplinary teams target the relief of symptom distress as a high priority, studies reveal significant symptom burden'.

And this does not begin to address psychological, social and existential suffering, which Frances Norwood describes as 'social death'. Dr Eric Cassell's erudite dissertation on suffering asserts that 'suffering is an affliction of the person' and 'suffering is a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted'. Dependency is an affront to integrity; sociology researchers Clive Seale and Julia Addington-Hall (*Social Science and Medicine*, 1995) found that 'fear of dependency is deeply rooted, and is not amenable to alteration by a programme of care'.

The 2014 Australian Palliative Care Outcome Collaboration (PCOC) reported that of patients in the terminal phase of their illness, 4 per cent had severe pain, 7.5 per cent had other severe physical symptoms, and 3 per cent suffered severe psychological distress. It is not surprising, then, that palliative care does not entirely succeed in the palliation of suffering. It is a monumental task, especially when you consider these self-evident truths: first, that intolerable and unrelievable suffering is common in terminally ill persons, and often escalates as death approaches; and, second, that some suffering is only relieved by death. Cicely Saunders was well aware of the complexity of suffering, coining the term ‘total pain syndrome’ to embrace all the facets of distress, physical, psychological and existential.

Another report, by Tanya Pidgeon and others (*British Medical Journal*, 2015) and based on patient accounts, stated that patients receiving palliative care in Australia have physical and psychosocial concerns that are often complex and rated as severe. One quarter of respondents reported severe pain, 20 per cent reported severe ‘other symptoms’, 20 per cent reported severe anxiety as patients, 45 per cent reported severe anxiety of family, 66 per cent expressed feelings of depression, and 19 per cent reported severe problems with self-worth. This research shows much higher levels of patient distress than does the PCOC study. As well, the 2016 Victorian parliamentary inquiry into end-of-life choices heard from patients, carers and health practitioners that there are people who continue to experience irremediable pain despite receiving palliative care. The task palliative care has set itself is especially difficult when you maintain, as an integral philosophy, that palliative care does not hasten death; and you are battling a constantly accelerating target, using a relatively poor tool kit.

Palliative Care Australia acknowledged in 2006 that it could not relieve all pain and suffering, even with optimal care. It could hardly do otherwise, with Professor Michael Ashby stating in the *Journal of Law and Medicine*, 'the idea that modern palliative care can relieve all the suffering associated with death and dying is a flawed approach'; and Roger Hunt writing (*Willing to Listen, Wanting to Die*, 2000) 'the hospice ideal of providing pain-free comfortable and dignified death is usually unachievable and should not be promised'.

However, Palliative Care Australia was being a little disingenuous because it did not disclose its trump card—terminal sedation. Terminal sedation has been defined as the use of drugs to reduce consciousness, for the treatment of intolerable and refractory symptoms in patients who have been diagnosed with advanced progressive illnesses. In practice, because such suffering is continuous and progressive, the sedation is almost always to unconsciousness, and almost always associated with withdrawal of food and fluids, although this is regarded as a separate decision. The effect of sedation to unconsciousness and withdrawal of food and fluids is to hasten death (whether the person is actually dying or not), so whether this is the cause of death in a dying patient may be difficult to determine.

In the late 1980s, continuous delivery of analgesics and sedatives together became possible when the Graseby pump, a syringe driver, was developed and the quick-acting sedative Midazolam was found to be compatible with morphine in a common syringe (recognised in palliative care as 'the pump' and 'M and M'). Emile de Sousa and Bridget Jepson from St Catherine's Hospice first reported (*The Lancet*, 1988) its use for 'terminal restlessness'. Palliative physician Alexandra Burke and others described (*Medical Journal of Australia*, 1991) terminal sedation as providing 'a readily available means of controlling symptoms and

overcoming patient distress where no feasible alternative existed previously'. In 1990, Ventafridda reported its use for 52 per cent of palliative outpatients, to howls of anguish from others who stated that they never, or very rarely, used it. Nevertheless, palliative expert Susan Chater (*Palliative Medicine*, 1998) found that 89 per cent of palliative care physicians believed that terminal sedation was sometimes necessary in the management of terminally ill patients: 'Over 60% of these patients had either pain or respiratory distress as the major symptom requiring terminal sedation'. One third had psychological issues, including fear, panic, terror and anxiety. More recent assessments have found its use to be steadily increasing—it was utilised in 14.5 per cent of all deaths in Flanders in 2007, and in 17 per cent of all deaths in the United Kingdom in 2008.

Physician Linda Emanuel (*Journal of the American Medical Association*, 1998) was so concerned by the death-hastening potential of terminal sedation that she proposed 'anaesthetic coma' for dying patients with intractable suffering. In her proposal, such patients would be placed in an anaesthetic coma, with full respiratory support and hydration and nutrition, to ensure that they died of their disease, not of the treatment. She wrote, 'while patients may continue for days in this state before dying, the patient is not suffering'. Thankfully, and not surprisingly, this approach has not been adopted.

Palliative medicine expert Andrew Billings and psychiatrist Susan Block described terminal sedation as 'slow euthanasia' (*Journal of Palliative Care*, 1996) to more howls of dissent. They famously defined 'slow euthanasia' as 'the clinical practice of treating a terminally ill patient in a fashion that will assuredly lead to a comfortable death, but not too quickly', and included terminal sedation in this definition. They were challenging the soft defence of intention, and focusing on outcome. They also asked 'Why

should a patient who requests a quick death be subjected to a slow dying?'.

The schizophrenic relationship between palliative care and terminal sedation is illustrated in these words from a grieving daughter. Her father, dying of cancer, had had inadequate pain relief but:

> we were finally introduced to the option of palliative care. A wonderful white knight palliative care professional actually listened to us. He acted on our feedback to increase doses when we recognised they needed increasing. Yet despite the most attentive care we could have hoped for, my precious dad still suffered horrendously. He was essentially unconscious yet every time the staff had to move him he screamed and howled in pain like a scene from a horror movie.

The use of terminal sedation has expanded to refractory pain, breathlessness, extreme fatigue, and psychological and existential distress. But, while it is very clear that palliative care has the tools to relieve intolerable suffering, I have never heard or seen it make this process evident to the public. Terminal sedation remains the Achilles heel of palliative care because it is used in circumstances where other doctors might provide assisted dying if they were asked. Furthermore, terminal sedation has patient consent in only about 50 per cent of such deaths, and offers little opportunity to say goodbye. If you do not acknowledge that the treatment that is about to begin will coincide with death, how do you suggest it might be a good time to say farewell?

Far from publicly acknowledging terminal sedation, palliative care has been assiduously arguing in its literature that neither terminal sedation nor morphine alone, if used in a proper palliative way, ever hastens death. Terminal sedation is justified for the treatment of refractory, or intractable, symptoms, as determined by the clinician, not the patient. Palliative expert Marco Maltoni and others stated (*Journal of Clinical Oncology*, 2009) that 'Despite the huge progress made in palliative medicine in terms of

symptom control, many are intractable symptoms, either because the treatment is ineffective or because the treatment itself is intolerable'.

However, in order to demonstrate that hastening death is not the intention, the drugs are slowly measured and adjusted, or titrated, to a level where consciousness is gradually suppressed, and thus, in association with withdrawal of hydration, death inevitably follows. It would be reasonable to assume that if symptoms were intractable, and death clearly imminent, there would be an imperative to provide maximal relief of any pain and suffering as soon as possible. Legally there is no problem with hastening death if the intent is to relieve suffering. For example, the Victorian Medical Treatment Act 1988 states that 'dying patients should receive maximum relief of pain and suffering', and the judgment by Justice Devlin in the United Kingdom case *R v Adams* allows for a legal double effect regarding intention. Nevertheless, titration is obligatory under the 'palliative model of care', with suffering continuing until unconsciousness ensues, which may take days. And this occurs despite senior consultant Robert Twycross (*Oxford Textbook of Palliative Medicine*, 1993) stating 'nothing short of deep unconsciousness could provide relief and ... inadequate sedation makes matters worse'. Professor of medicine and bioethics Erich Loewy wrote (*Archives of Internal Medicine*, 2001), 'Terminal sedation, we would claim, differs from some form of voluntary active euthanasia mainly in that it has not been and is unlikely to be legally challenged'. Justice Sandra Day O'Connor of the United States Supreme Court observed:

> The purpose of terminal sedation is to ease the suffering of the patient and comply with his wishes; and the actual cause of death is the administration of heavy doses of lethal substances. The same intent and causation may exist when a doctor complies with a patient's request for lethal medication to hasten death.

The early practitioners of terminal sedation clearly recognised its potential to hasten death. Palliative doctor Declan Walsh, commenting on the relief of dyspnoea, stated (*The Lancet*, 1993) that 'drug doses should be increased as required, even at the risk of hastening death from central nervous system depression'. Palliative specialists David Bottomley and Geoffrey Hanks noted (*Journal of Pain and Symptom Management*, 1990) that 'respiratory depression is more likely when Midazolam is used together with opioid analgesics'. Susan Chater recorded that 'the risk of undesirable outcome (shortening life) is acceptable only because of the more compelling need to act to relieve suffering'. In a 2000 *Lancet* editorial, palliative specialist Janet Hardy wrote, 'the stated justification [of terminal sedation] is that there is no other means of relieving intractable distress in a dying patient, and that it is morally reprehensible to leave a patient to suffer intolerably. The concept of sedation causes considerable unease in many palliative care workers, most of whom are ardently opposed to any form of euthanasia or patient-assisted suicide. There is concern that sedation as the best means of symptom control in the dying patient is underused because of fear of employing "terminal sedation"'. That is, the sedation caused, or contributed to, death. Roger Hunt summed this up when he wrote in *Willing to Listen, Wanting to Die*:

> When analgesics and sedatives are infused, the patient enters a kind of 'pharmacological oblivion' and appears at peace—it is usually assumed that in this state there is freedom from pain and distress. The patient cannot eat or drink, has a dampened cough reflex, develops retained airway secretions which 'rattle' and become infected, all of which hasten death. This is also true in a subjective sense, permanent unconsciousness is, in the patient's view, similar to being dead.

Jessica Corner, Director and Deputy Dean (Nursing) of the Centre for Cancer and Palliative Care Studies at Royal Marsden Hospital, wrote (*British Medical Journal*, 1997), 'the easing of death, as an intentional double effect, is common

in palliative care and general practice ... Palliative care needs to take the lead by making clear the strategies it employs for managing difficult situations at the end of life, and, when the double effect is used with a view that death is a likely and welcome secondary consequence, to be open about this'. She demonstrates refreshing honesty in recognising that death could be a welcome consequence of palliative care. Eminent British geriatrician and ethicist Professor Raymond Tallis reports the opinion of a palliative care physician that, despite the availability of terminal sedation, 15 per cent of deaths are 'bad deaths'; and that is the opinion of the doctor, not of a patient or their family.

The concern about hastening death is echoed by Catholic bioethicists Daniel Sulmasy and Edmund Pellegrino, who wrote (*Archives of Internal Medicine*, 1999), 'this rule [double effect] allows physicians opposed to euthanasia and assisted suicide to treat pain adequately in those situations with a clear conscience'—that is, it provides a justification for terminal sedation. They continued, 'as the critics point out, the rule of double effect is only morally important if euthanasia and assisted suicide are considered immoral'. Roger Hunt wrote perceptively (*Palliative Medicine*, 1999), 'there would be little or no need to invoke the principle of double effect if palliative care treatments never hastened death'.

People who are close to death will often cease eating and drinking, and there is no reason to provide these people with fluids. However, others with the ability, and perhaps the desire, to drink will be unable to eat and drink if consciousness is reduced. The withdrawal of food and fluids is not primarily a process that relieves suffering; in fact, it may induce suffering. Palliative care makes the valid point that the provision of fluids may result in fluid retention and increased breathlessness, but with impeccable titration this should not occur. The simple conclusion is that providing fluids in association with continuous and deep sedation

prolongs the period in coma, prolongs the dying process and is clearly futile.

Erich Loewy summed up (*Archives of Internal Medicine*, 2001) terminal sedation in these terms:

> In terminal sedation, not only is the patient's death clearly foreseen, it is in fact the end point of what is being done. Clearly (and however it may be cloaked by the use of language) the intent is more than just the clear goal of relieving pain and suffering. Because the goal of relieving pain and suffering can be obtained only by obtunding the patient until death ensues, the patient's death becomes the end point, and therefore one of the intended goals. These goals do not differ from those of physician assisted suicide, or, for that matter, voluntary euthanasia.

Loewy does not object to the use of terminal sedation. Indeed, he sees it as humane and necessary:

> Although such practice may shorten life, I do not in any way oppose maximal sedation and analgesia for patients at this stage of life. Indeed I can see no rational or humane argument against such a practice. But I do oppose the idea that we should engage in this practice for our own or the court's sake. Ethics, if it must be anything, must be honest. Twisting things or calling them by a different or more benign set of names merely obfuscates instead of addresses the problem.

Palliative care's acknowledgement that there can be refractory suffering that can only be relieved by terminal sedation to unconsciousness is a clear indication that some suffering will only end with death, and that there exists a necessity in this circumstance to hasten death. The only difference between this and assisted dying is, as Billings and Block point out, the time taken to hasten death.

End of life is where the physical meets the psychological meets the existential, and few doctors are adequately trained to meet this crisis. The palliative answer is to retreat into 'do no harm', to bring in the shrink and the priest, to experiment with more drugs to relieve physical symptoms, while completely ignoring the whole problem. Palliative care does see the problem, but does not see the need for a different solution.

Palliative Care Australia has acknowledged that patients do make rational and persistent requests for a hastened death—Roger Hunt found (*Palliative Medicine*, 1995) 25 per cent of his palliative care patients did so. Dr Linda Sheahan's research (*Internal Medicine Journal*, 2016) found that 15 per cent of palliative care physicians had requests at least weekly for assisted dying, and another 27 per cent at least monthly. Thirty per cent of doctors found it difficult to deal with these requests. Yet, Ben Rich (*Cambridge Quarterly of Healthcare Ethics*, 2014) found it is 'the view of a prominent segment of the palliative care professional community that almost without exception maintains that patients who receive state-of-the-art palliative care, including psychosocial and spiritual interventions, almost invariably cease and desist from their desire for a hastened death'. Surprising? No, as who has all the power is such discussions? Christian Koeck has no doubt (*British Medical Journal*, 2014)—'patients yield up power to physicians because one has knowledge and the other is apparently ignorant'. Could this not be seen as duress? Martin Klein asks (*Health Care Analysis*, 2004) 'does it really show more respect for the vulnerability and dependency of the dying to coerce them to receive palliative care?'

Why do people make these requests? Nurse and scientist Jean-Jacques Georges and colleagues from the Department of Public Health recorded (*Journal of Pain and Symptom Management*, 2006) that 'loss of dignity is tightly related to a feeling of hopeless suffering. Preserving one's dignity appears to be very important for patients and largely contributes to requests for hastening death'. His group also noted that 'The most frequent reasons for making a request for hastening death were loss of dignity (75%), general weakness (63%), and hopeless suffering (63%). Loss of dignity and loss of control over one's life were significantly more often mentioned in requests to hasten death than in

requests to forgo treatment'. Requests for some means of hastening death increased as the end of life neared.

Palliative doctor Jeffrey Kohlwes and colleagues wrote (*Archives of Internal Medicine*, 2001) 'the most common cause for a durable request for assisted suicide was existential suffering'. These authors also noted a professional code of silence, and difficulty in discussing these matters with colleagues.

The Philosophy of Palliative Care, written by experienced British palliative care physician Fiona Randall and moral philosopher RS Downie, subtitled *Critique and Reconstruction*, does indeed carefully dissect the rhetoric of palliative care. First, they explore the fundamental philosophy of palliative care as being based on religion:

> The roots of modern palliative care are of course to be found in religious orders concerned with the care of the dying. These orders had a conception of a 'good death' which involved acceptance of human mortality and recognition that human weakness and sin could be forgiven.

These ideas were fundamental to the modern hospice movement and are evident in hospices such as St Joseph's and St Christopher's. Randall suggests that concepts such as meaning, fulfilment and authenticity have become the substitutes of religious dogmas—the idea that each person is uniquely loved as a child of God becomes secularised as 'you matter because you are you'. Randall states:

> this sense of philosophy resembles a statement of religious faith. Firstly, it is similar in that no grounds for the assertions it makes are given, and indeed it may not be possible to prove the assertions in the way that statements of fact are proven. Secondly, its assertions are thought to express truths which are self-evident to professionals working in the field. Thirdly, like a faith, those truths are not self-evident to all people, for it is clear that many professionals working outside the context of specialist palliative care might not accept or follow the normative content of the World Health Organization's statement of PC Philosophy. For example, they would not consider that relatives should form part of the remit of care. Fourthly, its critics may be viewed as a threat, or perhaps are to be pitied, since they are unable to accept the truths self-evident to others. Lastly, it

> resembles a faith in that its articles declare not just what one ought to believe but how one ought to believe.

Randall believes that the many palliative care professionals have a philosophical or religious position about a good death that is then imposed on their patients. She states: ‘Our reply is simply that not everyone wishes this kind of end, and those that do are likely to be much better served by the clergy than palliative care professionals.’

Randall acknowledges that the core element of the original philosophy of palliative care was an emphasis on the primacy of the personal, of the needs and wishes of the individual patient. However, now ‘palliative care professionals, instead of listening to the sick patient’s needs, fears and wishes, and accepting these at face value, are encouraged and exhorted to impose professional templates’. She further points out that palliative care professionals are opposed to assisted dying, even if patients favour such a choice. This is hardly consistent with a philosophy that so heavily stresses patient-centredness, self-determination and choice. ‘Those unfortunate individuals who are pushed around in a heteronymous way by others from the outside, or those who have their decisions made for them, lack dignity: but if you are able to make your own autonomous decisions then you exemplify dignity.’

Finally, it becomes clear that palliative care attempts aspects of care that are inappropriate or unachievable. Commenting on the psychological reaction to dying with great suffering (described in palliative care as ‘demoralisation’) she states: ‘we would question firstly whether this natural reaction to the end of life situation actually requires intervention, secondly whether it is in any meaningful sense “measurable”, and thirdly, whether the effectiveness of such an intervention can be assessed only by a numerical intervention’.

Randall is critical of the exaggerated claims made by palliative care and of the harm they may cause. Ultimately it becomes clear that palliative care attempts types of care that are inappropriate or unachievable. She writes: ‘The goal of “impeccable” relief of pain and other symptoms is unachievable, and the expectations generated by the philosophy are unrealistic. Setting unachievable goals for one set of people, and promoting unrealistic expectations (which will not be met) in another group of people, is unfair to both and likely to lead to harm for both’ and ‘Palliative medicine claims to alleviate emotional, psychological, social, and spiritual suffering, in addition to physical symptoms. There is no other specialty which claims to do all these.’

Randall’s summation of the claims made by palliative care is penetrating, coming from someone with deep experience of the practice:

> the inflated and often contradictory claims made in the literature of palliative care—its rhetoric … which cannot, in reality, be enacted in clinical practice. The language of palliative care offers an ‘impeccable’ assessment and treatment of pain and other symptoms and ‘exquisite’ and ‘meticulous’ nursing care … This is embarrassing rhetoric. Palliative medicine claims to alleviate emotional, psychological, social and spiritual suffering, in addition to physical symptoms. There is no other specialty which claims to do all these.

Palliative medicine makes such claims for people who are dying, a time of acknowledged suffering and great distress—claims for relief of not only physical symptoms but also those of a psychosocial and spiritual nature. Palliative care is a brave, even noble, enterprise, tackling some of the most difficult problems in medicine, which doctors for many years avoided. It deserves support and encouragement, yet its claims must be justified, and it must be open to criticism. Randall’s book is welcome for doing this from within. For too long palliative care has been able to make extravagant claims in order to deny others choice.

Ben Rich stated in 2014 in the *Cambridge Quarterly of Healthcare Ethics* that 'Others have raised concerns about an authoritarian streak, or a form of hard paternalism, in the philosophy and practice of hospice. Those concerns denote a perception that some in the hospice movement maintain a rigid and monolithic view of death: one size fits all; it's the hospice way or the highway'. He may well have been reflecting on this statement by philosopher Ellen McGee (*Journal of Palliative Care*, 1997): 'Hospice presents one such clear position—hospice maintains that it has a vision of good dying; it presents an ideal of continued care, of valuing the individual even when he does not value himself'.

Julia Lawton wrote, 'The research highlights the difficulties of matching the modern hospice movement's ideological goal of enabling patients to "live until they die" with the realities of the ways in which many patients, cared for in hospices, bodily degenerate in practice' (*The Dying Process—Patients' Experiences of Palliative Care*, 2000).

Palliative care has been described as a 'model of care', which has become more and more defined and specialised, into which the patient must fit. Professor David Clark, Professor of Medical Sociology at Glasgow University, observes (*The Conversation*, 30 March 2016) obvious failings and shortcomings, citing the furore over the Liverpool Care Pathway, and poor reports on end-of-life care from the United Kingdom Ombudsman and the Care Quality Commission. The Liverpool Care Pathway was an example of such a model of care. Designed by palliative care experts as a model to guide end-of-life care in hospitals, it failed because it did not treat people as individuals and ask what care they wanted, leading to abuse of autonomy. We are all individuals, shaped by our own experience and values; for government to suggest that we should all fit into a specific 'model of care' is extraordinary.

Ian Maddocks, the first Australian professor of palliative medicine, states that 'The roots of modern palliative care

are of course to be found in religious orders concerned with the care of the dying', and that 'Palliative care usually has adopted a confrontational position against voluntary euthanasia, partly because of the historical association with Christian (Catholic) concern to preserve life'.

Dr Alastair Bonnin, a palliative medicine colleague, declaring himself an atheist, responded by email:

> I also thank Professor Maddocks for acknowledging the hidden influence of religion … A doctor with a faith-based belief in the sanctity of God-given life cannot be other than opposed to euthanasia and assisted suicide. This does not invalidate his or her opinion per se, but when presenting views as an expert professional, such fundamental influences should be openly acknowledged.
>
> Censorship of diverse views is not confined to the RACP. The Australian & New Zealand Society of Palliative Medicine recently polled its members on a proposal to amend its Position Statement to declare euthanasia and assisted suicide unethical, and to expunge an acknowledgement of the diversity of views held by members and the public. The proposal was carried by an unspecified majority, and thus my specialty society rendered diversity invisible.

Bonnin's observation regarding palliative care's position statement on voluntary euthanasia and assisted suicide is pertinent. From 1995 to 2006, the position statement of Palliative Care Australia included three important statements: it recognises that there is a wide range of views in Australian society, and also within the caring professions, about the deliberate ending of life; it recognises and respects the fact that some people rationally and consistently request voluntary deliberate ending of life; and it acknowledges that, while pain and symptoms can be lessened, complete relief is not always possible, even with optimal palliative care. These realistic statements were not in the 2008 statement and have not reappeared, while, at the same time, Palliative Care Australia states that it has developed a 'position of studied neutrality' on this issue. However, Palliative Care Victoria's submission to the 2015 parliamentary inquiry stated, 'Palliative Care Victoria has

given this issue in depth consideration and does not support the legislation of euthanasia or assisted suicide'. This is hardly 'considered neutrality'!

Associate Professor Alex Broom spent six months conducting intensive patient interviews in a Catholic hospice, talking to doctors, nurses and patients (*Qualitative Health Research*, 2011). He found an atmosphere of tension, death in the air; a place of unbounded and hopeless bodies. Patients had a sense of impotence and entrapment, being subdued within the hospice's ideological frame.

Broom found among the patients virtually unanimous support for assisted dying, but that the hospice was totally opposed. A desire for hastened death was seen as a call for help; the patient 'just needed more time' to adjust, and their request was met with spiritual and social support. The assessment would be that it was 'not their time to go'. Assisted death was not part of hospice care, which had an ideological model of dying, based on religious contexts.

He also found an underlying Catholic influence in the hospice. Although it was a site of medical care, it had Christian underpinnings, and an interplay of religiosity that was rarely explicitly acknowledged, care precariously placed between that of the body and of the soul. Broom points out that Pope Benedict XVI's 2009 statement that 'Euthanasia is a false solution to the drama of suffering' reflects the wider influence of religiosity in shaping what palliative care and the medical profession will allow, and the state support.

Ellen McGee clarifies (*Journal of Palliative Care*, 1997) a significant (though not universal) view within palliative care:

> The hospice is a shared moral community with a shared notion of what is right and best for the patient.
>
> Since its inception, hospice has seen itself as a moral enterprise: it shares a vision of what constitutes 'good dying'. This moral vision is unique in the secular health care field and animates hospice's answer in particular ethical dilemmas.
>
> Hospice offers a vision of living and dying which does not accord with the view that one should rationally choose a hastened death.

Derek Doyle wrote effusively (*Journal of Pain and Symptom Management*, 1992) about spirituality in palliative care:

> A human is not human if he or she never asks ‘Why do I suffer? Who am I? Where is God? What is it all about? For the first time they have doubts about God’s readiness to forgive, find it difficult if not impossible to articulate prayers, and rebel against what is happening yet must, at all costs, maintain an outward appearance of serenity and unshakeable faith.

And then he declares, ‘Suffering is potentially creative’! There is almost a sense of salvation being a hidden component of palliative care. After all, Pope John Paul II determined that there ‘is salvific value in suffering’.

Cardinal George Pell proudly states that the Catholic Church provides 57 per cent of Australian palliative care. There is no other area of Australian medical practice that is so infiltrated by a specific moral framework, and there can be no doubt that the religious origins of palliative care, and religious dominance in its provision, has a profound effect on how people die. It is profound because Catholic bioethics prevails in Catholic palliative care, and Catholic bioethics is very different from mainstream bioethics. The latter is not constrained by a particular moral framework, and, clearly, has reached different conclusions regarding end-of-life ethics.

It was notable that of the submissions the Victorian parliamentary inquiry into the end of life received, those most vocally opposing assisted dying came from the Australian Christian Lobby, the Australian Catholic Bishops Conference, the Melbourne Catholic Archdiocese, the Australian Family Association, Palliative Care Australia and the ANZ Society of Palliative Medicine. Dying, though, is a personal and private matter and should not be decided by a few powerful stakeholders.

Catholic Health Australia does not agree with the interpretation of personal autonomy that holds ‘the

individual is the ultimate source of decisions about treatment and care'. It claims that the Catholic approach preserves traditional morality—morality as it has been worked out in western civilisation from the beginning. The Catholic account holds that ultimately our lives belong not to us but to God, as the Creator of human life. It supports the principle of acting in the best interests of the individual but with the proviso that within the Catholic framework of end-of-life decision-making, decisions that respect the individual's wishes regarding treatment may not always be able to be met.

The attitudes of, predominantly Australian, palliative care physicians were revealed in a paper by oncologist and ethicist Dr Linda Sheahan that confirmed 85 per cent were opposed to assisted dying. This is in complete contrast to the general population they serve, 80–85 per cent of whom support it.

Such views are underpinned by the principle of the sanctity of life. A group of interfaith leaders (Anglican, Presbyterian, Methodist and Jewish) in the United Kingdom said in 2012, 'We believe in the sanctity of life, but not in the sanctity of suffering'.

Palliative medicine professor Sam Ahmedzai, a critic of euthanasia (by direct injection), but a supporter of assisted suicide (by oral self-administration), wrote (*British Medical Journal*, 2012):

> It is patronising to say that a few people should suffer unbearable distress and indignity because palliative care preaches that it values all lives—regardless of how meaningless they have become to their owners. It is inconsistent for palliative care to boast how it enables people to face the reality of dying and decide about place of care but then to deny choice for timing of death. Moreover, it is hypocritical to deny competent patients who are acknowledged to be dying, the right to die in a manner of their choosing, while allowing doctors and nurses to place them on a so called care pathway, which often entails increasing sedation and withdrawing fluids—unintentionally leading to a protracted form of assisted dying, but one that is medically determined.

Let us consider the above in the light of my final self-evident truths. First, a doctor has a duty to relieve suffering. Sir William Osler wrote over 100 years ago that a doctor's duty was to 'ease death'. Second, a doctor has a duty to respect their patient's autonomy.

Palliative care places great emphasis on respect for autonomy and patient choice, but it is autonomy and choice in a straightjacket—you can have choice, but not the ultimate choice of when and how you die.

Palliative care will control that. Palliative care professor Norelle Lickiss stated (*Medical Journal of Australia*, 1995), '[I]t is my conviction that a doctor must be the boundary bearing the pressure of society and individuals in the matter of euthanasia. Autonomy of the individual cannot be the ultimate guide to action. I would contend that the interests of the individual are best served by refraining from euthanasia'. So, palliative care judges whether your symptoms (including psychological and spiritual/psychosocial suffering) are refractory—that is, in the opinion of the palliative care doctor, are unable to be relieved. It does not accept your judgment that your symptoms or suffering are intolerable. It will determine whether you will receive palliative sedation, and at what rate these drugs will be provided and increased. It will control how and when you die.

Given these fundamental ethical obligations, should a doctor who is treating a patient with intolerable and unrelievable suffering and who asks for assistance to die only offer refusal of treatment, slowly progressive sedation to unconsciousness, or refusal of food and fluids? This is what the American Academy of Hospice and Palliative Medicine (AAHPM) suggests. Its 2007 position statement contained three offers to suffering persons whose request for assistance to die could not be deflected: refusal of life-sustaining treatment; refusal of food and fluids (without any mention of what palliation might be offered for additional

suffering); or ‘palliative sedation, even potentially to unconsciousness, if suffering is intractable and of sufficient severity’. Just how a doctor will determine whether suffering is intractable and of sufficient severity is unclear, given they have no effective way of measuring it. The suffering person has no control over the initiation of sedation, its rate of implementation or its depth.

Although the vast majority of palliative care physicians oppose assisted dying, there are some eminent voices to the contrary. Dr Nancy Hutton, Medical Director of the Community Hospice of Maryland, who is a Director of the American Academy of Hospice and Palliative Medicine, took a neutral position on assisted dying in 2007. She said, ‘Doctor-assisted dying is not the antithesis of palliative care. I think it’s taken as a way of providing comfort for unrelieved suffering. And so, in that respect, it would be consistent with a palliative care approach’.

Since assisted dying’s legalisation in Oregon nearly twenty years ago, hospice has flourished and accepted it in its framework. In Belgium, one of the best providers of palliative care in Europe, assisted dying has been integrated into it. Professor David Clark stated (2016) that ‘In locations where either physician assisted suicide or euthanasia are legalised, there is no evidence this inhibits the development of palliative care’.

In 1995, Professor Michael Ashby wrote (*Medical Journal of Australia*), ‘It is not the role of any health-care team to suggest that its ministrations can give meaning, purpose and dignity to a dying person’s remaining life if that person feels that these are irretrievably lost, although sometimes this perception will change, either as a result of palliative care or for other reasons’. He also noted, ‘Palliative care is a model of care, not a moral crusade, and should not be used as a strategic weapon in social debates’, and ‘Those caring for people making such requests [medical assistance in dying] should continue to offer and deliver care without

allowing personal religious beliefs to intrude into the clinical encounter'.

Ashby supports legislation allowing assisted dying, but is concerned about its effects on palliative care practice. Professor Ian Maddocks also supports 'decriminalisation' of voluntary euthanasia but is wary of its impact on palliative care practitioners.

Armed with thirty years of palliative care experience, Dr Larry Librach states (*Ottawa Sun*, 7 November 2007), 'We used to say palliative care would relieve all suffering, but that of course was nonsense. I've seen too much suffering to be glib about it anymore'. Palliative care professor Allan Kellehear said at the Dying With Dignity Victoria AGM in 2000, 'If you can stand it no longer I would understand your wish and your act to go. I would support your autonomy because you are a free citizen in a multicultural society, and not the plaything of clinical and religious institutions'. Contrast this with Ellen McGee noting that (*Journal of Palliative Care*, 1997), 'The philosophic stance which envisions the individual as always needing to be in control, as never being vulnerable, never a burden, and never in need of care, is in the hospice vision incomplete'.

Professor David Clark makes the obvious point that those in palliative care and advocates for assisted dying have collective aims—to relieve suffering, to support dignity and to respect autonomy—but remain at loggerheads largely because of differences in interpretation. In the opening paragraph of its submission to the Victorian parliamentary inquiry, Palliative Care Victoria (PCV) stated, 'the values of compassion, dignity, respect and choice are important to us all and are integral to the provision of high quality palliative care and end of life care'. DWDV would agree. Yet, DWDV supports assisted dying and PCV opposes it. Again, religion is the fundamental difference. It is not objectionable that palliative care holds such opposing views, but it should

openly acknowledge why it holds them and not impose them on non-believers.

In some respects, this stand-off reminds me of the Reformation—a reform movement arguing for respect for individual conscience and autonomy challenges an intransigent dogmatic Catholic position. Having often wanted to pin my theses to the door of Melbourne's St Patrick's Cathedral, I wonder if palliative care needs a Martin Luther figure to challenge its assumptions. I have long admired Martin Luther's statement to the Diet of Worms in 1521—'I cannot and will not recant, for it is neither wise nor salutary to act against one's conscience'. In fact, a reformation in palliative care has already begun, in Belgium and Oregon to name only two places, and will undoubtedly continue. Unfortunately, it will cause a schism in some countries where a strong religious view underpins it; I suspect this is what Ian Maddocks and Michael Ashby want to prevent.

So, again, I ask does palliative care's rhetoric stand up to reality and the honest examination by senior practitioners within its own ranks? The religious influence affects the philosophy and practice of palliative care—the rigid adherence to not hastening death relegates relief of suffering to a lesser role. Its approach to symptom relief for the dying is reactionary, not anticipatory, and some still believe there is value in suffering. For example, I heard of one woman who, when complaining about her sister's appalling suffering while she was dying in a Catholic hospital, had a nurse tell her she should be grateful that her sister 'had been chosen to share the agony of Christ'.

Palliative care's claim to provide and respect choice and autonomy falls short of what the community at large understands these to be. In palliative care, the sanctity of life trumps personal autonomy, but in law the reverse is true. Palliative care is a noble enterprise with an exceedingly difficult task. It does not make it any easier by adhering to a

philosophy based on values that are not consistent with the community's. Reliable polls have shown that even many people with religious faith do not support opposition to assisted dying.

I am not opposed to palliative care. I support open and frank communication between a dying patient and their doctor, and a patient being helped to go as far with their life as possible. I also support encouraging the acceptance of the reality of dying; maximal relief of pain and suffering; giving a patient a sense of control over the end of their life; respect for patient autonomy; and encouraging dialogue between a dying patient and their family, with the important object of allowing them to say goodbye—all good palliative principles. But I do not accept the rigid imposition of a particular model of care, and a limited choice at the end of life, which condemns some people to die in a way that is anathema to them, in order to satisfy their doctor's moral view.

I believe palliative care would be enriched and would develop by honestly acknowledging its limitations, and by ceasing its opposition to assisted dying. There is abundant evidence that it will not be harmed by this, and if, in time, it integrated assisted dying, it will become more loved and respected than it is today. That said, I want to make it clear that there is rarely any complaint made against palliative care nurses. They are widely admired and respected. It is they who provide the care in palliative care, and the doctors who provide the palliative medicine. The care is exceptionally good, but the medicine is not always so good.

In fact, nurses have been found to have a very different view of assisted dying from doctors. In 1992, bioethicists Helga Kuhse and Peter Singer published research (*Australian Nurses Journal*) that revealed 78 per cent of Victorian nurses favoured law reform to allow doctors to perform euthanasia. In 1994, a survey of South Australian nurses by Christine Stevens and Riaz Hassan (*Medical Law*) found that 60 per

cent were in favour of legalisation of active euthanasia under certain circumstances. In 1997, a survey of New South Wales nurses (NSW Nurses' Association, November 1997) found that 80 per cent supported a change to the law to allow voluntary euthanasia in some circumstances. At the same time, polls of doctors were revealing majority support but to a significantly lower degree than by nurses. Nothing has changed since. The Australian Nursing and Midwifery Federation (Victorian Branch) (ANMF) made a submission to the 2015 Victorian parliamentary inquiry, stating:

> However reform is needed in relation to the terminally ill health consumer having a legal right to request their treating medical practitioner prescribe medication to consume or to inject voluntarily with the intent to end their life with dignity and with all the available safeguards in place through access to legal advice and appropriate professional treatment by qualified and specialist health practitioners.

ANMF stated the following principles:

> Competent adults with a terminal or advanced incurable illness that creates unrelievable and intolerable suffering shall have the right to choose to die with dignity in a manner acceptable to them and shall not be compelled to suffer beyond their wishes.
>
> In the case of a competent adult, with a terminal or advanced incurable illness that creates unrelievable, intolerable suffering, it shall not be an offence for health practitioners to confidentially advise the sufferer and/or relatives and guardians regarding end of life choices; nor to assist or support the sufferer in choosing to hasten death in a manner acceptable to themselves; nor to be present at the time of death.

This second principle is very significant. Nurses are health practitioners, and are clearly signalling their desire to be legally able to continue to support a patient through their journey to the end, in whatever way that person chooses. These nurses also need protection. Palliative care specialist Michelle Gold said in her evidence to the Victorian parliamentary inquiry (*Sydney Morning Herald*, 23 July 2015) that 'sometimes pain relief was withheld or given in lower doses because hospital staff were scared'. She added

‘change in palliative care moved at a glacial pace in Australia’.

I have no argument with our magnificent nursing profession, only with a small section of the medical profession who wish to impose their model of dying on everyone else.

The AMA (Victorian branch) submission was, by comparison, focused on protecting doctors, and entirely ignored the issue of assisted dying. It is true that protecting doctors through effective laws will benefit patients, but that is essentially strengthening the status quo. The gulf between the attitudes of the medical and nursing professions was on stark display. There was no doubt as to who was more aware of patient suffering. It stares nurses in the face, day and night.

My experience over twenty-five years with end-of-life counselling of more than 1500 people has taught me an invaluable lesson—and my last self-evident truth—that giving people control over how their lives end is one of the most valuable palliative tools we have. Palliative care would be enhanced by using this tool. If only palliative care could recognise and acknowledge the value of open dialogue about assisted dying, and of some physician assistance in dying, how much better off both palliative care and the community would be.

7

DIGNITY, VULNERABILITY AND BURDEN

Assisted dying is such an emotive area, about which there are such differing viewpoints, that it is worth considering in more detail the three concepts that constantly recur in discussions about it.

Dying with dignity; what does it mean? Death is the moment when all brain function ceases, but it is more easily recognised at the point the heart stops and breathing ceases. It is an outcome, an instant of time that quickly leads to a permanent and inevitable state. At the moment of death, most people will be unconscious, either due to their illness, or due to medical intervention, so having a ‘peaceful’ moment of death is common in our society. A ‘wild’death, in which gross unrelieved pain and distress occurs, is, fortunately, rare.

On the other hand, dying is a process (not an outcome) that often takes place over at least some hours or days, but can also take weeks, months or even years. Moreover, we are usually aware of what is happening to us when we are

dying, which makes dying far more important than death. While the moment of death may be peaceful, the process of dying is not often so.

I think these matters are easy to understand, but dignity is far more complex, because it is a notion, not easily defined, an idea, a concept; something which we perceive but are unable to measure. And that perception is an individual matter, depending on our values and experiences. It is not an absolute quality. We are all different, so we each have a different perception of dignity.

Some theologians and religious philosophers endeavour to give dignity an absolute character, stating that every person, no matter their physical or mental condition, has an innate dignity that demands respect. Pope John Paul II argued that Terri Schiavo, an American woman who had been in a deep, persistent vegetative state and supported by PEG feeding for fifteen years, still had dignity. I agree that every person, irrespective of their circumstances, deserves respect, but not because of some notion of innate dignity. If I have a devout belief in a God who will decide when I will die, I will be prepared to accept as dignified any circumstance that befalls me before death. However, when it comes to dignity in dying, it is *my* perception of it that matters, not that of an ivory tower philosopher or priest who is ignorant of my circumstances.

We are not aware of dignity when we have it, but are painfully aware when we lose it. It is immeasurable. As human beings, it is one of our most precious goods. Dignity has a number of definitions and shades of meaning, but in relation to dying, calmness of manner and serenity of mind are paramount. Loss of dignity can vary from mild to total loss, bringing to mind degradation, desolation and humiliation. Moreover, one person’s perception of loss of dignity is not necessarily another’s, but it is important to remember that it is not the other person who is in the predicament. The thought that a particular circumstance

that mortifies you is water off a duck’s back to another does not lessen your distress. Shakespeare, as usual, said it best, with ‘there is nothing either good or bad, but thinking makes it so’; what for one person is a loss of dignity may for another be a problem solved.

What, then, are the factors that create dignity in dying? Not surprisingly, many are those that create dignity in life. We aim to develop a sense of who we are and where we fit into society, a persona, a sense of worth, serenity of mind. These, and having a sense of purpose, are inherent to our own dignity. We make constant adjustments as our lives change, to re-establish our equilibrium, a sense of calm and control, and thus restore our dignity if it’s been disturbed. But when we are faced with dying, restoration of equilibrium becomes more difficult, or is perhaps even seen as impossible.

The dying process is often accompanied by suffering that is simplistically seen as obvious physical suffering, primarily pain. However, like dignity, suffering may be invisible and unmeasureable. Breathlessness is obvious, as are loss of appetite, and weakness and wasting, but the dependence that follows them may not be so obvious. Incontinence is an obvious and humiliating loss, but the psychological suffering of dying people is less obvious. Loss equals suffering, and there are many losses in the dying trajectory. There is the loss of a sense of purpose, and thus of a sense of worth, loss of any sense of enjoyment and a role in life, and loss of a sense of control over your life. These can all be seen as existential losses, or existential suffering; losses that go to the heart of our perception of ourselves and thus are a threat to our dignity.

Many people in western societies are brought up to admire unselfishness; to be selfless, as is a mother with her child. A sense of being a burden to one’s family, friends and carers is a profound source of suffering and leads to a loss of dignity. No matter how much we are reassured we are not a

burden, and so even if the burden is willingly assumed, we may detest imposing it. Such a sense of burden is commonly associated with severe dependence, and its accompanying humiliation.

Psychological and existential suffering is just as important as physical suffering, and for some people may be more significant. For these people, the sense of a loss of control is central, creating a range of psychological reactions ranging from anxiety and frustration to fear, and even to terror. A depressed state of mind may, understandably, follow, but this may be virtually untreatable without changing the underlying cause or prevailing circumstances.

These myriad problems must be dealt with to restore dignity in dying. To have dignity, you need to escape from what is causing indignity to return to a sense of calm. It is extremely important to respect others' sense of dignity when they are dying. By all means, you may gently try to counsel them that their perception of a loss of dignity may be based on shock, anxiety or depression, and be able to change over time. But to disparage or deny their perception is insulting and harmful. Palliative care emphasises maintenance of hope, but hope is based on the possibility of a better future, which is unlikely when someone is dying and facing a crescendo of increasing suffering. The one effective hope that can be offered is the restoration of control. Apart from effective control of pain, it is the best palliation a doctor can provide.

Much of the restoration of dignity for a dying person comes from good palliative care. Finding a new sense of purpose, establishing strong family and community connections and abolishing loneliness, eliminating symptoms of physical and psychological suffering, and promoting acceptance of the reality of dying are all vitally important, and the sooner they happen, the better. Honest, open communication between doctors, nurses, carers,

family, friends, and the dying person is critical to protecting the dying person's dignity.

So, the most important aspects of dying with dignity are to die free of suffering—or, at least, without intolerable suffering—and with a sense of control. As suffering is intensely personal and cannot be measured, all suffering is ultimately in the mind. The suffering of two people in what seem to be identical circumstances may be very different, and no stigma should be attached to someone who seems to suffer more. We should make every effort to relieve such suffering in the mind, but if we cannot, we must respect it.

With a sense of control, you are free of the toxic anxiety that destroys the serenity of mind essential for dignity. That sense of control applies to the place, time and manner of death. It involves accepting the reality of death, of knowing when you are dying and being able to say goodbye. How you die is important not just to you but to those who survive and grieve your death. Cicely Saunders said, 'How people die remains in the memories of those that live on'. So, a good death with dignity is profoundly important in diminishing the grief of those left behind.

For some, dying with their head held high, proud and in control, dying with a bang and not a whimper, is essential. For others, dying quietly, with peace and security, and surrounded by their family, may be the ideal. For someone else, leaving it to their doctors and trusting they will be treated with respect is what matters. But if, after appropriate discussion, someone says, 'I want to go now,' that should be respected because it is an essential part of their dying with dignity.

Who are the vulnerable people? Opponents of voluntary assisted dying are very fond of stating that the frail and elderly, such as 'grannies', are 'vulnerable patients' who will be pressured to request assisted dying by mendacious

relatives, intent on hastening death in order to acquire a legacy.

There is also a group of competent, not terminally ill, disabled people who express concern about assisted dying. This group, as represented by an American organisation called ‘Not Dead Yet’, is highly visible, highly vocal, well organised and apparently well funded. They purport to speak for all people with disabilities, but their activities have led other groups of disabled people to express support for assisted dying being legislated (usually those with more advanced and progressive disabilities). The argument Not Dead Yet puts seems to be that, first, such legislation would lead to devaluation of the lives of the disabled; and, second, would lead to great pressure on the disabled to end their lives.

The first of these is a throwback to the Nazi regime, the argument about eugenics that opponents of assisted dying constantly bring forward. But is there any evidence today that doctors devalue the lives, or disregard the wishes, of the disabled? Why would this change if the right to choose a hastened death were available? And, of course, what this argument overlooks, quite deliberately, is that in all legislative proposals, the choice resides with the individual, not the doctor. Moreover, there is no evidence from jurisdictions where voluntary assisted dying is allowed that abuse of the disabled has occurred. Professor Linda Ganzini stated (*JAMA Internal Medicine*, 2016), ‘Concerns that legalization of physician-assisted death would undermine efforts to develop and improve palliative care programs and target vulnerable groups such as the elderly population, the uninsured, and the poor have not been realized’. The argument results from opponents trying to create fear, uncertainty and doubt, without a shred of evidence to support their claims. Its basis is that if you repeat a lie often enough, it can become a truth—the basis of propaganda.

The second argument suggests that disabled people who do not really want to die will be pressured to do so because of societal, or perhaps family, pressure. Not only is this argument not supported by any evidence, it defies experience and logic. All legislation, and all legislative proposals, require a person requesting assistance to be interviewed by at least two doctors; sometimes, a third psychiatric opinion is also required. From the last twenty-five years of experience with counselling dialogues about end-of-life matters, I can say that such discussion focuses deeply on the reasons for the request, and can readily detect ambivalence, disordered thought and external pressure. What is more, there must be both a written and oral request, which need to be witnessed by disinterested parties. I do not think it is possible for such scrutiny, by up to three doctors, to fail to discover when people are making requests under external duress. What is more, the necessity to self-ingest medication creates a significant barrier to possible abuse.

When it comes to logic, it is well established that, unless a person is depressed even if not physically ill, they will cling desperately to life, even against great odds. They cannot be persuaded to end their lives simply because someone else thinks it is a good idea. It is, of course, possible that someone in a position of power might abuse another so badly that the consequent suffering drives the person to consider taking their own life. But that can happen without a legislative change; and if it were to arise because of a legislative change—that is, a doctor were expected to assist in the death of an unwilling and abused person—the phalanx of medical assessment would be certain to detect it. The evidence from jurisdictions where voluntary assisted dying is legal makes it clear that doctors are very cautious in applying the law, and that negligible abuse has been reported. When doctors have been prosecuted for error, or neglecting to follow guidelines, examination of the context

of the assistance has found the fault to be technical, rather than heinous.

Canadian senator Chantal Petitclerc spoke during the 2016 debate on the Canadian assisted dying bill, C-14. Paraplegic since the age of twelve, she was commenting on the exclusion of those with advanced incurable illness from being able to choose. She said:

> an even bigger problem … not allowing the right to access medical assistance in dying to someone who is in unbearable pain but is not dying denies a whole group of individuals the right to choose how they want to live and how they want to end their lives. They are the most vulnerable, and we have an obligation to protect them. A person who is vulnerable is not without rights and deserves to have those rights respected. Let us have safeguards, guarantees to protect the vulnerable.
>
> But let me tell you, there is nothing more frustrating, when you are a person with a disability and vulnerable, than to feel as if you have no control over your own life. When you have a disability, the worst part is feeling as if you have no control over your own life and your own body. It happens to all people with disabilities, I can promise you that. It happens to me from time to time … The more severe the disability the more vulnerable you are, the bigger the betrayal feels. I can only imagine how someone would feel if they were vulnerable, in great pain and unable to have control over their own choice. That, to me, would be a betrayal not only of the body but also from our country.

The second ‘vulnerable’ group that opponents of assisted dying refer to are the frail elderly who are obstructing inheritances by avaricious relatives. It is alleged that pressure and abuse occur to obtain signatures on wills, ownership of property, and control and disposal of assets. If the law on, for example, financial power of attorney is ineffective, it should be amended. It is one thing to pressure an elderly person to sign a document they cannot understand, but another to persuade them to take lethal medication (apparently against their will), and to imagine that two doctors, bound to determine the competence and sustainability accompanying a request, would not detect this charade.

I agree that these frail elderly people are vulnerable. However, this is not in terms of being pressured to do things they don't want to do, but in terms of being unheard and disrespected regarding their wishes for end-of-life care.

The Victorian Medical Treatment Act allows for the appointment of a MEPA who can refuse medical treatment for an incompetent person that can result in their death that might allow earlier access to assets. The Act acknowledges that malpractice can occur, and places penalties on anyone attempting to influence such decisions. In practice, though, the Victorian police have not had reason to investigate anyone under this code in the nearly thirty years since its implementation.

MP Battin and others investigated (*Journal of Medical Ethics*, 2007) the question of vulnerability, and came to this conclusion:

> where assisted dying is legal, there is no current evidence for the claim that legalized PAS or euthanasia will have a disproportionate impact on patients in vulnerable groups. Those who received physician assisted dying in the jurisdictions studied appeared to enjoy comparative social, domestic, educational, professional and other privileges.

This, among other things, led Justice Lynn Smith of the Supreme Court of British Columbia to find that there was no risk to 'the vulnerable' in reform of the law around assisted dying (*Taylor v Canada*, 2012). She wrote, 'the empirical evidence gathered in the two jurisdictions does not support the hypothesis that physician-assisted death has imposed a particular risk to socially vulnerable populations'.

So, who are actually the vulnerable?

Sociologist and physician Nicholas Christakis, having described how 40–70 per cent of Americans die in pain, wrote (*British Medical Journal*, 2008):

> Yet one of the most compelling explanations of this sorry state of affairs is that those in our society who are dying constitute a particularly disempowered, even if numerous group. It may be fashionable in medicine

> to think about ‘vulnerable populations’, but it is hard to imagine a more vulnerable population than the dying, nor one that is more neglected or more invisible.
>
> We do not see marches of terminally ill people demanding recognition of their rights to more resources and more attention.

The simple fact remains that a dying person is in the weakest position they have been since they were a small child. They are extremely vulnerable to abuse by many; yes, family and carers, people they should be able to trust. Often such treatment is less abuse than lack of interest and respect, or neglect. Lucky are the dying who have family determined to protect their interests. Even more fortunate are those with well-informed representatives, who, knowing their rights under the law, will stand up to ignorant and bigoted doctors who ignore those rights.

These are the actual, not the theoretical, vulnerable. And, as Battin explains, legislation protects them from abuse.

Then there is ‘burden’, which is a hotly contested issue in the end-of-life debate. Proponents of assisted dying see it as a central component in why people might choose to die, whereas opponents see it as something that can be dealt with if only society tried harder.

What is a burden? The *Oxford English Dictionary* provides a number of options: a load, something carried or borne, or something difficult or grievous to bear; or the imposition of a burden (of any kind) upon, or to encumber, or to oppress with a burden. Finally, there is burdensome, meaning troublesome, oppressive, cumbersome, grievous to bear.

These are all relevant, but, from a dying person’s perspective, the notion of ‘imposing a burden upon’ is the most relevant of all. This is because they perceive themselves as a burden being imposed on those they love, which, for many, is not consistent with their deeply held values.

In a conflict between idealism and reality, some wonderful people who care deeply for the dying believe they should pick up this burden, and the sufferer be relieved of it.

This highlights the two sides of the burden coin: the burden of suffering borne by the dying person; and the burden imposed on, or passed on to, those who have to care for the sufferer. Irish geriatrician Desmond O'Neill wrote (*British Medical Journal*, 2011), in the context of John Donne's 'No Man is an Island':

> Not wishing to be a burden is in turn a different type of burden on those who care for and love us and a rejection of the deeper truth that our autonomy is, in the final analysis, exercised in the embrace of others. It undermines the urges, however imperfectly executed, that we all develop as a result of the care and nurture of those we love: it also erodes the universality of dignity as a quality that is not affected by disability or care needs.

O'Neill chose to focus on the role of friends and family as carers, rather than on the suffering of the individual. The suggestion is that the sufferer must bear the burden for the benefit of family and carers.

These are idealistic sentiments, and sentiments that most loved ones of a suffering person would want to emulate, and many do. There is no doubt that some relatives who are carers gain strength and purpose from it, but it may be too much to ask another to suffer more in order to be able to be cared for. This is perhaps selfish on the part of the carer, whereas the sufferer's desire to cast off the burden may be a selfless act. These conflicts are why there must be open discussion of end-of-life wishes so that values are well understood before a crisis occurs.

There is no doubt that accepting the burden of caring can be a long-term proposition the carer bears with difficulty and cost; and that is exactly what the sufferer may wish to avoid. What is the burden on the carer? Dr Michael Rabow and colleagues (*Journal of the American Medical Association*, 2004) researched this, and found that families play

important roles in the practical and emotional aspects of patient care, and in decision-making at the end of life. At the same time, family members may carry significant burdens:

> We describe 6 burdens of family care-giving—time, logistics, physical tasks, financial costs, emotional burdens and mental health risks.
>
> Care-giving can take as little as a few hours a week, but, commonly, it is equivalent to a full time job (20%).
>
> Laborious care-giving is often performed by people who are themselves elderly, ill and disabled.
>
> In a study of caregivers of patients with mild to moderate dementia, care-giver depression negatively affected their assessment of the patient's quality of life.

Researchers from Griffith University found (*International Journal of Geriatric Psychology*, 4 March 2013) that among 120 dementia carers (who were family members), 26 per cent had contemplated committing suicide. They had high levels of burden, with anxiety and depression.

Dr Harvey Chochinov (*Journal of Pain and Symptom Management*, 2007) found that 'Studies of patients who are terminally ill consistently identify strong associations between "sense of burden to others and marked end of life distress"'. This study of 211 palliative care patients with end stage cancer measured 'burden to others' and found 23 per cent were in the highest range:

> There is mounting evidence that sensing oneself to be a burden to others may be paramount to existential extremis … Among dying patients who actually killed themselves, feeling a sense of burden to others was almost universal … One of the few studies to specifically examine burden to others among dying patients noted its close relationship with existential, psychological, and to a lesser extent physical, symptoms, often seen towards the end of life.

So, the sense of being a burden is not trivial. RJ Kowhles and others found that (*Archives of Internal Medicine*, 2001) 'The primary reasons for requests [for assisted dying] fell into three broad categories: physical symptoms,

psychological issues and existential suffering. And the most usual cause for a durable request for assisted suicide was existential suffering. The feeling of being a burden on others was another form of existential suffering'.

And this is not a modern phenomenon. A story from Aesop's Fables goes:

> One day an old man having chopped some wood loaded it onto his back. He had a long journey to make. Worn out from the exertion he laid down his load and called Death. Death appeared and asked why he was summoning him. The old man replied: For you to pick up my burden.

To me, the critical question is: who is central to the problem? Carers must be ready to listen, to allow open dialogue and be ready to 'let go'. The imposition of the carer's wish to continue caring inflicts increasing suffering on the person they are 'caring' for. This is idealism writ large, but can be unrealistic—there are limits to caring, and there is potential for harm to both the cared for and the carer. Although a carer may willingly accept the burden of someone who is dying, this does not necessarily mean the burden is resolved. It can remain a burden for the sufferer—they simply do not want to pass it on, because they know that, although it is willingly accepted, it is still a burden. That may be something that their most fundamental values cannot accept.

8

THE MEDICALISATION OF DYING

There is an unintended consequence of the care of the dying. Palliative care, in the dominant position it now has in the care of the dying in modern western societies, aims to provide real comfort to those who are dying: to support them, and relieve their symptoms as much as possible. It has brought compassion, warmth, touch and company to many people who were otherwise dying alone. To do this well requires carefully organised provision of services, with rules and regulations as to how these services will be provided. Thus, it has developed into a model of care, provided by a 'team'.

Unlike the traditional one-to-one relationship of doctor and patient regarding decision-making and treatment, there is now a group discussion, with a doctor, nurse, social worker, psychologist or psychiatrist, and spiritual/religious adviser. Often there will be more than one doctor (both a specialist physician and a GP), and a number of nurses involved in care, all of whom have a view, which may swamp

the patient’s view. Ultimately, the dominant view is the medical one—therein lies the control of medications—although in much home-based palliative care, the nurses’ view is powerful, because it is they who provide the essential warmth, touch and conversation. It is also the nurses who, after an initial medical assessment, provide further assessments of medication and care needs.

Families, if they are understanding and involved, are an essential part of a good death, which should be a shared experience. To die alone is a great tragedy, but it happens far too often—in hospitals, hospices and nursing homes, often in an induced coma after prolonged suffering. Tolstoy’s character Ivan Ilyich, in the novella *The Death of Ivan Ilyich*, died after prolonged suffering, despite attentive doctors and family. He could not engage with them because they were attending to his body, not his person; his only real human communication was with his lowly servant. He finally gained peace when he accepted the reality he was dying, shed his anger and fear, and gained enlightenment. The modern-day Ivan Ilyich, stern medical critic of the ‘medicalisation of death’, railed against the dehumanisation of dying and the intrusion of medical technology such that many deaths only occurred after the last possible, and sometimes totally futile, invasion of the human body.

Palliative care railed against this too but, in my opinion, has gradually fallen into a similar trap, in that its medical model of dying has become predictable and constrictive. It has created its own medical way of managing death—in the hard cases, with the ‘pump’ and ‘M and M’. Death is accompanied by a slowly induced coma, and withdrawal of food and fluids, a grim and often inadequately explained scenario. This too is a medicalised death, by formula and process; I have seen it, I have carried it out when I had no alternative, and I hate it. It is soulless, lonely, and harmful to families, and ultimately to carers. Remember that Cicely

Saunders said, ‘How people die remains in the memories of those who live on’.

I also have distaste for the practice of voluntary euthanasia, by which I mean delivery at an appointed time of a lethal injection, which, unlike terminal sedation, produces death in a few minutes. It also is a highly medicalised procedure, requiring medical expertise (insertion of an intravenous line, not always simple in a dying person, is needed) and a medical appointment for the ‘event’. Imagine making an appointment to die—Tuesday at 3 p.m.! What if the sun were shining, your grandson had visited at 1 p.m., and the moment was not quite right? Do you cancel the appointment? But when might the doctor come again? Will they come again? Might they doubt your commitment? If they do come again, how can you not go ahead with it?

Margareta Pos describes (*The Monthly*, May 2013) her grandfather’s death in the Netherlands:

> The night before I left, Diego, the younger of my Dutch half-brothers, called. ‘I thought you should be prepared. It’s going to be Friday at 9 pm.’ Arriving on Tuesday night—it’s been postponed until Saturday. The doctor was too busy on Friday night. He’s giving flu shots to elderly people on Friday night and couldn’t make it on Thursday night either.

Quite apart from me, as a doctor, coming to terms with the incredible emotional challenge of another person’s life ending by my needle, the crudity of making an appointment for it is unconscionable. The person must select a moment, not a space in an appointment book. It must not occur before it must; nor should it occur later than it ought.

The only person who knows when that moment has arrived is the sufferer, and even they do not know when that will be. Many people think they will end their lives to end their suffering, but find that moment keeps moving into the future. It may never come; they may die naturally. It takes

considerable courage to face your own mortality, and bring your life to an end.

Voluntary euthanasia by lethal injection does have advantages. Provided that secure intravenous access is obtained, a certain, quick and exceptionally peaceful death is assured, and the family can gather to say goodbye. Whether the person requesting the injection is competent can be confirmed beforehand. But what if they are not competent? Or what if they were competent when consent was discussed but are now impaired? These issues continue to cause problems in the Netherlands. Though competence may be lost, the suffering does not disappear—it may get worse. Dementia is the most obvious example.

The least medicalised death is sudden, without warning. Then there is the slightly less sudden death following a dramatic and unexpected event, and a short hospitalisation, to no avail—either because of uncorrectable damage or medical futility—such that treatment is withdrawn. Both of these situations have the disadvantages of producing a sense of catastrophic loss, and no opportunity to say goodbye. This is of incalculable importance. The sense of loss and therefore profound grief that arises from such circumstances is before us almost every day on television news bulletins.

Life is precious, so everyone wants to live as long as possible, providing their life has sufficient quality and meaning for them. People therefore involve the medical profession when disease or injury threatens their existence. We voluntarily engage with it at the end of our lives, both to find out what our future holds and to ease our death. We want honest communication about these matters, but often don’t get it. The fault lies both with the doctor who dodges the issue of honesty in communication, and with the dying person and their advocates for not insisting on the truth. Good communication is at the heart of a good death.

A minimally medicalised death can be achieved with dialogue between the doctor and the suffering person. I will now use the word ‘patient’, as its literal meaning is ‘a person who suffers’, but its meaning has evolved to be ‘a sick person who seeks advice and often treatment from a doctor’. Doctors speak of the doctor–patient relationship (patients tend not to use this language) because it puts them in the box seat. They have all the knowledge, and therefore all the power; they have a frightened customer who will usually accept their advice as to what should happen next. What the patient needs is an honest appraisal of the situation—not what might be done or what new experimental treatments might be available, but what that doctor would do if they were in that situation—a good question to ask.

A dialogue commencing well before death, perhaps on first receiving the news of an incurable illness, will allow that person and their doctor to establish a rapport. This should be a *patient–doctor* relationship, which is not just patient centred but patient directed. They should be able to discuss making an agreement that if intolerable and unrelievable suffering should develop, the doctor would, on request, provide medication to allow that person to control the end of their life. The doctor should, of course, have the right not to make such an agreement.

Such a conversation can have quite an amazing effect. While the matter may never be raised again, the calm and comfort such a dialogue produces are deep and lasting, provided there is trust between the ‘patient’ and the doctor, with them having developed a ‘patient–doctor relationship’. Nothing, however, cements that sense of calm as much as the actual provision of medication—the provision of control over the end of life.

Dying belongs to the person who is dying, not to the doctor. The dying person is not someone for the doctor to control or dictate to—they should be listened to, their

concerns heard and responded to. Once the doctor is convinced that the person's suffering is intolerable and unrelievable, or will soon become so, the provision of medication has profound palliative value. Control over the end of life passes from the doctor to the suffering person, where it should be. This does not mean the doctor has no further role. They should continue having a dialogue with their 'patient', providing other symptom relief, advice and support, and the understanding that the medication will not be ultimately used without a final discussion.

Relief of fear and anxiety does not occur simply with obtaining medication—clear instructions on the consequences of ingestion and the effect of it on those close to the dying person are essential. Family, and sometimes friends, are an important part of this dialogue; death should not be a lonely affair, unless the dying person wishes it to be so. In my view, it is essential that a suffering person's family fully understands why they feel the need to end their life—because they want their suffering to end—and that they support that decision and agree to 'let go'. The shared end of a loved person's life is a special moment. Until they have that experience, in the optimum circumstances, most people are unaware of its profound, even beautiful, quality.

Giving someone control over their own death means giving them medication they must ingest themselves. This means that nothing will happen unless they make the critical decision—they have total control. This is of the utmost importance—unless they are convinced of their decision, nothing will happen. They do not need a doctor—they can determine when, or if, and where, their life will end. The doctor is irrelevant at this point, though essential at an earlier time.

For that dying moment to be profound and beautiful, it needs to occur with certainty, dignity and serenity and peace—the occasion needs to be calm. It may be the suffering person will feel comforted by the presence of the

doctor they trust and who has guided them. I have been present on a number of occasions when people have died through the oral intake of pentobarbital (Nembutal) that I have provided.

While there is a textbook of different medications that can or might cause death in different circumstances, they may have unpredictable outcomes regarding the comfort experienced and the time dying takes. Therefore, nothing comes close to Nembutal. With the proper dose, and with prophylactic anti-emetic medication, a gradual sleep develops over about three minutes. Conversation can continue during this time but gradually ends with a yawn; and from there sleep progressively deepens until death occurs, almost imperceptibly. It is hard to determine when this is, it is so gradual and quiet, but is usually in fifteen to twenty minutes. Most family members, having not witnessed this before, are astonished at the ease of death. This gradual passage to the end of life also allows time for reflection on precious moments.

Quite apart from the very important aspect of non-medicalisation of dying, there are other major ethical reasons for my preference for personal ingestion. I have the greatest respect for any rational person’s decision to end their life if faced with intolerable suffering, and I do regard that as a decision they, and they alone, can make. Therefore, they have responsibility for that decision. If they are responsible for the decision, they are responsible for carrying it out, unless they are physically unable to do so. This is rarely the case, and I have never been in a dialogue with someone who did not accept that argument about responsibility. Ultimately, taking your own life is the most autonomous act that you can do.

The only circumstances where a person could not exercise personal control over the end of their life would be if they could not swallow or absorb oral medication, or they were totally paralysed and unable to act on their own behalf.

These are the sole situations in which I would personally deliver a lethal injection. As a consequence of this ethic, I have never delivered a lethal injection to any person at any time. It has never been necessary.

To me, the question of the necessity to end intolerable suffering is fundamental. At times there is a medical necessity to relieve suffering, and that may only occur through hastening death. I believe that if, and only if, a rational suffering person requests this, a doctor must respond. And assisted dying by provision or prescription of oral medication is the least medicalised dying that I know.

9

DYING WELL, DYING BADLY

Australians want better death. They want to choose when, and with whom, they die. Most want to die comfortably at home, supported by family and friends, if they can. This is clear from a March 2015 report on dying well by Melbourne think-tank the Grattan Institute, *Change to die for?* In it was a synopsis headed ‘What does it mean to die well’, which summarised the views of those interviewed for the report.

Change to die for? reveals that half of Australians die in hospital, and about a third in residential care. Seventy per cent of people want to die at home but only about 14 per cent do so. It lists what people want for the end of their life:

- They want to know when death is coming and to understand what can be expected.
- They want to be able to retain control of what happens.
- They want to be afforded dignity and privacy.
- They want to have control over pain relief and other symptom control.

- They want to have choice and control over where death occurs (at home or elsewhere).
- They want to have access to information and expertise, of whatever kind is necessary
- They want access to any spiritual or emotional support they require.
- They want to have access to hospice care at any location, including home, not only in hospital.
- They want to have control over who is present at, and who shares the end, with them.
- They want to be able to issue advance directives that ensure wishes are respected.
- They want to say goodbye, and control other aspects of the timing.
- They want to be able to leave when it is time to go, and not have their life prolonged pointlessly.

It is notable that at least six of these wishes have a central concept of choice or control, coinciding completely with what my experience with dying people has revealed. Given that these are the considered views of Australians, how well do the ways we die measure up?

We die in a wide range of contexts, but these can be distilled to some typical ways. Only a small number of people die suddenly, or in their sleep, without any medical involvement. More frequent are violent deaths by suicide; deaths by refusal, or withdrawal, of treatment, usually occurring in hospital or another institution; deaths managed in palliative care; deaths managed at home by GPs; deaths by voluntary euthanasia (lethal injection); and deaths by assisted dying (oral ingestion), and occasional deaths by refusal of food and fluids.

On 26 August 2015, the Victorian coroner, John Olle, provided evidence of violent suicides, by people who were not terminally ill but had unrelievable suffering, to the Victorian parliamentary inquiry. The deaths included a

middle-aged man with colorectal cancer who hanged himself in a public place; a quadriplegic teenager who bled to death after lacerating his lower limbs; and a middle-aged man with unrelievable chronic spinal pain who ingested stored medications. These deaths, and those of another 240 people over a period of four years, certainly did not meet Grattan's desired criteria. Many of these people had advanced incurable illnesses, including neurological diseases such as Parkinson's disease, chronic organ failure and chronic pain, and they could not find relief via the medical profession. Tragically, they took things into their own hands and died violently.

This phenomenon is not confined to Victoria. The Demos foundation in the United Kingdom did a similar study, and found that approximately 2 per cent of all suicides were by people who were terminally ill, but approximately 10 per cent were by people who were chronically ill. They reported that 'in all of the sixteen interviews with multiple sclerosis patients ... the participants reported loss of control as precipitating suicidal thoughts'.

Withdrawal of treatment is generally a medical decision based on the treatment's futility, and often occurs in intensive care units—all too frequently according to palliative care specialists Charlie Corke, Peter Saul and Ken Hillman. While aware research has shown that, on average, 33–38 per cent of patients near the end of their lives receive non-beneficial treatments in hospital, they continually find themselves involved in withdrawing intensive treatments of elderly people with incurable illness, who should have been involved earlier in sensible communication and effective decision-making. Withdrawal of treatment should occur in the person's home or a nursing home, but, regrettably, many GPs do not make home visits in emergencies, so the emergency-department-to-intensive-care roller-coaster occurs without the relevant documentation. Our nursing homes seem to be ill equipped to provide appropriate

palliation to dying patients, and the position regarding refusal of treatment is little better. A substantial number of doctors are ignorant of the law: that any competent person can refuse any medical treatment, even if such refusal will result in death; and, even more importantly, that these people should receive maximum relief of pain and suffering.

Such refusal includes voluntary refusal, by a competent person, of food and fluids; the legal position is clear that such an action is not suicide, and that effective palliation should be provided. This clearly did not happen to Rudi Dobron, who I talked about in Chapter 1, but did happen to my patients Jane and Howard, as discussed in Chapter 2 and in *A Good Death.* The coroner reviewed their deaths and found them to be 'natural'. Jane took nine days to die, but was unaware of any suffering for the last seven. The question why anyone who is suffering intolerably should have to go to such extreme lengths to obtain relief is one that our society cannot come to grips with.

Queensland senator Ian McDonald has told the story of how his beloved mother lived for seven years in a hospital after a severe stroke paralysed her right side in 1983. This robbed her of most of her mobility, speech and quality of life. Despite teaching herself to write with her left hand and to say 'yes', 'no', and 'I love you', six years after her catastrophic stroke she had had enough. She began spitting out her pills, then refused to eat and drink. But it took seven months of starvation for her body to finally give in. At this point, her doctor said to her, 'It's time now, Mac, isn't it?' She responded with a weak nod, the doctor performed some action, and she died. It is astonishing that choosing to die over a period of some days by refusing food and fluids, with medical assistance, should be legally possible, yet choosing to die in minutes by ingesting medication, with medical assistance, in similar circumstances, is not. The AMA reported a new position on forced feeding in 2013, stating that doctors should respect the wishes of people who have

made an informed and voluntary judgment to refuse food (*The Age*, 10 April 2013).

Dying by dehydration, if one has the determination to ingest nothing at all, or by starvation, if you take some fluids, can be rendered more comfortable with good nursing and effective medication, but takes days or weeks, and an incredibly strong will. Palliative care assures dying people who cease eating and drinking that exquisite mouth care will prevent any suffering. Even if the physical suffering can be minimised, though, the psychological pain of being forced to this extreme must be appalling.

Cancer is probably the disease that palliative care manages most often, and there is a perception it does this very well. Rudi Dobron did not think so; nor did Ann McPherson, a British doctor, who wrote of her experience with pancreatic cancer that ‘death is seen as technological defeat. Palliative care specialists see it as failure if patients want an assisted death. I think that’s ridiculous. It should be part of good palliative care’ (*The Independent*, 24 January 2011). Her daughter Tess, also a doctor, described her mother’s last weeks, dying in pain with an ‘unbounded body’ discharging copious amounts of fluid (*British Medical Journal*, 2012). Tess described how her mother, diagnosed in early 2007, battled the disease for three years, finding her life with cancer worth living, even with many ‘new normals’—such as regular morphine to control pain; having an afternoon nap; at times smelling toxic; having a chest drain, which she drained daily; and eating only baby food. She put up with these, and other distressing changes, and was always grateful for the medical support and interventions that made it possible for her to continue to work, to spend time with friends and family, to enjoy the days she knew were so precious.

Finally, it came to a crisis. The cancer had spread around the gastric outlet, so that Ann could no longer eat anything solid and even fluids were difficult for her to manage. Her

chest drain had started to leak and was pouring out fluid that drenched her dressings. She had lost a lot of weight. She was getting pressure sores. She had had enough:

> She had a morphine drip for the now uncontrollable pain and discomfort. Mum said that she hoped to drift away that night, but there was no drifting away. What followed was three weeks of living agony. She was morphine tolerant. She felt ill in a way that only dying people can feel, and she knew she would never feel any better. She resented life now. She no longer enjoyed seeing people, could no longer eat or walk, and could barely talk. But she did manage to express that she felt 'bloody awful' and would rather be dead.
>
> There was no dignity, there was no Mum, just a wounded animal. My brother and sister were up and down from their homes and families. They were not coming to say goodbye—that had been done weeks earlier—just to sit hopelessly. It is an honour to care for someone you love, but it no longer felt honourable to try to care for someone who wished to be dead. Without assisted dying our mum died slowly and in pain.

While United Kingdom palliative care is reputed to be the best in the world, David Cade does not think so. He reported on his partner's mother's final six weeks of life in 2012:

> She was moved to a hospice from hospital after doctors perceived that death was unavoidable. They found she had a large tumour growing at that point in the head where the nasal passage meets the back of the mouth. It was inoperable, partly due to her advanced age and partly due to the location. This tumour made it very difficult to breathe through either the nose or her mouth. It also made swallowing completely impossible. So for six weeks she suffered continually from the pain of hunger and had to struggle for breath.

It was utterly cruel, inhumane, and unmerciful for her to be forced to endure such a situation for those last six weeks. No doubt all the nurses and doctors who administered palliative care, as the patient moaned with hunger and gasped for breath, felt they were doing their best to make her comfortable, but her agony continued. Palliative care did not relieve her suffering. It wasn't good enough.

John Paynter's wife died in palliative care in Canberra Hospital in 2016, and he told her story to *Canberra CityNews* (1 June 2016). She was dying of metastatic melanoma, but

this was not openly discussed with him or his wife. She had pneumonia, and when she developed cerebral symptoms was subjected to yet another scan. Her last words to John as she went into the CT scanner were ‘I’m scared’. When the scan revealed brain lesions, all treatment, including antibiotics and fluids, was withdrawn, with scant discussion with John. Gradual titration of analgesics and sedatives commenced. He said, ‘for the first few days she was constantly gurgling and coughing in an attempt to clear her throat. She appeared terrified. After much complaining on my part they finally included the sedative in her continuous feed [injection]. On day five, she was still groaning and trying to cough, sometimes almost screaming’. After John complained further, they tripled her dosage of sedative and pain medication. ‘On day six, she was getting weaker and sometimes just couldn’t get a breath’; by day seven, ‘she finally got so weak that she stopped trying to cough and just breathed more and more shallowly. I was alone with her, my head on her pillow and holding her hand when I noticed the breathing had stopped. At last the poor thing had some peace—after seven days of unnecessary and unbelievable cruelty’. No doubt palliative care would regard her death as ‘peaceful’—one of the staff told John that ‘only God can take a life’.

Graham Lovell’s presentation to the Victorian parliamentary inquiry about his wife’s palliative care experience in Melbourne’s Alfred Hospital is hauntingly similar. Graham described her death as ‘terrible’. He remained with her through nine days of withdrawal of hydration, and inadequate levels of medication; he had to fight to get her morphine and sedatives to relieve her pain and suffering. He believed she died a ‘barbaric death’, and stated, ‘I do not want to see other totally vulnerable people suffer and die in pain’.

Journalist Beau Donelly told the story of MS sufferer Anthony Virgona, and of how he was starting the process of

ending his life (Sunday *Age*, 7 February 2016). Anthony was fifty-five, and had lived with MS for twenty years, and in a nursing home for twelve years. He had only one kidney and had been on hospital dialysis for three years (having it three times a week). He could no longer walk. His short-term memory was gone. A team of carers washed, dressed, fed and toileted him. He said, 'My bones are starting to buckle. My spine hurts. I'm in too much pain for too many hours of the day' and 'I've been fighting this disease for 20 years and I've just had enough'. He had decided to cease dialysis, and would die from renal failure over about three weeks. He would have preferred taking a pill and going to sleep, rather than dying slowly of renal failure. Still, Anthony said his overwhelming feeling was one of relief and being at peace: 'I feel good about my decision. I'm not ashamed, I'm not really afraid'. In case you think I am being selective in reporting these stories, let me say I have a significant file of similar 'bad deaths'—there are too many to include.

Palliative care does not only provide support for cancer patients but also for those with motor neurone disease. MND is characterised by inability to swallow, even your own saliva, leading to episodes of choking due to ineffective coughing, and respiratory failure—this is a difficulty for which ultimately nothing can be done. It is the pinnacle of palliative futility. David Armstrong wrote of his wife Deb's final days with MND (*The Australian*, 4 March 2003). He was told, 'You won't want to see it and you certainly won't want the girls to watch their mum going through it. When the time comes, call me and we'll put her into hospital and make her comfortable'. David did not know what that meant, and his wife was determined to stay at home. Within three days of respiratory failure beginning, she became highly distressed, physically and emotionally, as she struggled to breathe. She eventually found peace through an increase in her morphine.

This story highlights the dilemma of dying at home. Although this is what many people want, the overwhelming physical and emotional demands of caring for someone at home, particularly when they have a slowly evolving illness, can be enormous and beyond even the most caring family's resources if the dying process is to go to its natural end.

What alternatives are there? The writer Peter Robb, in his book *Lives*, told of a conversation with intensivist Dr John McCarthy about a man with advanced MND. He had been admitted to the intensive care unit for breathing difficulties, but then insisted on going home, and Dr McCarthy acquiesced to his request, despite his wife's protestations. McCarthy added that patients often died at home—they took an overdose or their family gave them one. 'When the time comes, death will find a way,' he said. Realistic, yes, but it leaves the family, with no knowledge of drugs, to struggle with a frightening moral and legal dilemma that the medical profession should not handball.

Who has sufficient knowledge of drugs to provide a good death? A general practitioner, perhaps, but not necessarily. I have been approached by GPs for advice about medications that end life, been referred patients to give such advice because the GP had no knowledge of it (or perhaps stomach for it), and been approached by GPs for advice about their own end-of-life needs. This is not a subject that medical textbooks or lectures address—empathetic doctors have to learn through experience, and by inevitable mistakes.

One experienced GP told me of his initial involvement in an assisted death. P was gay and had developed Kaposi's sarcoma, an affliction often associated with AIDS. It affected his mouth and nasal cavity, causing severe pain, ulceration and bleeding. He required frequent and increasing doses of oral morphine. At the same time, he was experiencing wasting and becoming dependent. His treating GP had become a close friend, after some years of careful disease management and home visits.

P challenged everything his GP stood for when he asked him for help to die, though the GP determined that P was quite rational and had no further options. He sought advice from P's infectious diseases consultant, who knew him well and advised that such assistance was justified. Thus, after a farewell party on P's birthday, the doctor administered a sedative injection, and then an intravenous dose of 1000 milligrams of morphine (about fifty times the normal dose). The doctor had never done this before, and had warned P that, because of P's long-time use of morphine, calculating a lethal dose was guesswork. So it proved to be. P went deeply to sleep for some hours, but did not die. Nursing care was arranged for him in his home, and further massive doses of morphine administered over the next five days, until P finally died. This was not a good death, due to the unpredictability of morphine for this purpose. P probably did not suffer, but his end could not be described as dignified, and was very stressful for the doctor and P's friends.

Another doctor, who remained anonymous, told of a patient, Cle, who had bowel cancer, with secondary cancers in the liver and lungs, in a story with the headline 'A doctor's confession: She took my advice and died as planned' (*The Age*, 5 February 2016).

She had tried every avenue for a cure, including alternative treatments overseas. Cle had many fears about her future, and her greatest fear was of losing control over her body in the final hours and days leading to her death. A friendly doctor gave her advice about obtaining medications for a fictitious insomnia, and advised her on an appropriate dose.

Cle became weaker, and lost weight, energy and hope. She spent most of her time resting at home, her family supporting her. An episode of breathlessness saw her admitted to hospital, with a diagnosis of heart failure brought on by the tumours in her lungs. Oxygen and medication brought a little relief. Cle put on make-up, did

her hair, and told jokes and stories, laughing as she had not done in weeks. Each of her family members had time with her alone, to share their thoughts and feelings at an intimate level. When her partner visited the next morning, she told him she had taken her tablets. He rang her medical adviser, but she had died by the time he arrived, fifteen minutes later.

That doctor wrote:

> I have had many patients since, some of whom have been approaching death. None since Cle has asked me for advice on how best to end their life at a time of their choosing. If, and when that question comes again, I hope I can help them without fear of prosecution. I believe the laws need to be changed, so that each of us when we face our death can take at least a little control. As did my first patient, my mother Cle.

On this occasion, advice about prescription medications was successful in assisting with a good death, but it is often an unsuccessful lottery.

By contrast, Dutch businessman Marc Vlessing told the story of his mother's death, via voluntary euthanasia, in the Netherlands. He describes the Dutch Termination of Life on Request and Assisted Suicide Act 2002 as the 'height of civilisation'. His mother, Rietje, a terminal cancer patient, opted for euthanasia in the summer of 2014, after being told she had two to four months to live. On 11 June 2014, Reitje celebrated her eighty-first birthday in hospice, surrounded by her children and grandchildren. She told the grandchildren that she would not be seeing them again—she was 'resolute and unsentimental'. Two days later, knowing his mother's death was booked for 5 p.m., Marc, with his sister and father, arrived just after lunch with candles, flowers and champagne. Gathered around the bed, they talked about old times 'and laughed until we wept'. In the midst of all this jollity, there was a knock on the door, 'like in a Mozart opera'. The doctor entered and explained that he would administer an initial injection that would put

Rietje to sleep in ten seconds; and a second one to paralyse the heart, which would take up to three minutes. She died smiling. Marc says, ‘It was the most beautiful, life-affirming way for us as a family to see her go. I don’t think anything more exceptional has ever happened to me, or will ever happen to me. It was even more extraordinary than the birth of my children’.

Another Dutchman, Freddy, working as a GP in a geriatric ward in Yorkshire, wrote (*British Medical Journal*, 2016):

> I have seen many people die, but none have died as peacefully as my gran. My gran’s death was my first encounter with euthanasia, and it made a lasting impression on me. She died at home on the anniversary of my grandfather’s death. My gran had carcinoma of the rectum with liver metastasis. She was troubled by severe fatigue, but loss of dignity was her prime concern. She had no physical pain, and she was alert up to the last second. She died through active euthanasia in Holland. All those who had watched her suffer—the long nights, the fatigue, the hopelessness—were incredibly relieved. We had seen her become very depressed. Her consultant said afterwards that this was one of his reasons for being a doctor, to relieve suffering this way. Is there any reason why this is not part of my duties as an English doctor?

Yet, the renowned American author and surgeon Atul Gawande said (*Being Mortal*, 2014) the Dutch Act was a failure: ‘Our ultimate goal, after all, is not a good death, but a good life to the very end’. A fine ideal, but very difficult to live up to. In 1998, palliative care specialist Michael Barbato said of one of his patients, ‘he prepared for his death; he died in his own bed after saying goodbye to his wife and family. It was one of those deaths we in palliative care hope to see but rarely do’.

By comparison, an Oregon doctor assisted, as allowed under statute, an 80-year-old woman with cancer, who wanted to die at home, rather than in a nursing home. He wrote, ‘She was able to choose the time and place. She died in the bedroom that she and her husband had shared in the house they had built, surrounded by her five children. It was very peaceful. The family was very grateful’. The similarities

to those of Barbato's patient are impressive; yet the death in Oregon is lawful and regularly achievable, but in palliative care in Australia it is rare.

While such a death is legally possible in Oregon, it is relatively infrequently chosen (less than 1 per cent of all deaths), but does occur within hospice practice. It fulfils all the Grattan Institute criteria for a good death. In Australia, such a good death is arguably illegal, and probably unusual, yet no one really knows because such assistance is hidden.

While palliative care's stated aim is to relieve suffering at the end of life but not to hasten death, these principles can come into conflict, particularly with sufferers of MND. A nurse wrote to me about her mother's experience of dying of MND in Catholic palliative care.

> Recently I was privy to a death which was cruel and tortuous. It has left an indelible mark on those of us present and the resultant torrid memories have become firmly entrenched within our minds scarring our lives forever. It was not a peaceful and gentle death but one devoid of dignity and compassion. It was an ugly death.
>
> This describes the death of my beautiful, gentle and courageous mum. Her death was insufferable, the type of death which we all fervently hope to be spared. None of us can envisage the exact circumstances of our death. We all hope for a peaceful end to our lives but suffering in death is indiscriminate upon whom it inflicts.
>
> My mother was diagnosed with what is now commonly referred to as 'the beast', Motor Neurone Disease. Mum's decline was extremely rapid and within 2 months of diagnosis she was unable to talk. We all fear losing our sight or hearing but as we rapidly learnt the inability to speak is devastating. Unable to utilize modern technology, communication through written language was frustrating, tiring and onerous. Unlike a vocalized fleeting thought, permanence is attributed to written words. Consequently it became progressively more difficult for mum to express personal and intimate thoughts.
>
> Before mum was deprived of her speech we had talked about dying, her expectations of death and the manner in which she would most probably die. She did not want to suffer. Naively with faith in a system I knew to be plagued with legal and ethical issues I felt reassured by medical staff that this scenario would not eventuate. Never for a moment did any of us envisage the horrors of MND to which she would succumb. Twice my parents were reassured that there would be no suffering at the end.
>
> Soon after losing her voice she struggled to swallow fluids and had a PEG tube inserted to ensure she remained hydrated especially over the oncoming

summer months. It was not long before eating became extremely difficult.

The care in palliative care during these stays was exemplary. It is impossible to describe the dedication of all the staff. Their compassion was palpable and care admirable. Around this stage, mum managed to convey to us that she wished to die in hospital. Once again this incredibly selfless woman, who had given so much to everyone during her life, was again thinking of others and did not want to die at home where she knew dad would continue to live.

Mum's condition became unmanageable at home. She was in severe pain and afflicted with many other conditions as well as the MND now ravaging her body. She returned to palliative care, to the incredible nursing staff and placed our faith in a system which we hoped would provide mum with the death devoid of suffering that she had been promised.

It was by now evident that mum was dying. She was suffering physically and mentally. Everyone who loved her, family, friends and many staff members had all become silent companions to her suffering. Mum's last few days will be etched in our minds forever. Acknowledging that mum was dying, her plan of 'care' was changed. It was decided that as she was dying, she would no longer be fed or hydrated. She was however to be given analgesia to provide 'adequate' pain relief and her anxiety would be similarly controlled. Distressingly several times in the last few days she motioned to us. I will never forget the moment she held up her PEG tube motioning us to feed her. Mum also managed to convey when she was in pain and most distressingly was able to communicate that she was afraid. We had been assured that she would be unaware of her plight. Allowing this to occur is surely reprehensible. Some family members pleaded and pleaded that she be given extra pain relief to not just manage her pain but to hasten imminent death. My request for similar management for mum was interpreted as a request to 'kill' and interpreted as a request to engage the medical staff in a criminal act. I found such emotive language extraordinary and extremely offensive. We did not want mum killed. All we desperately wanted was to see an end to her suffering.

I look back now in sheer bewilderment and amazement. The inability to adequately communicate was the cruellest of assaults. We know that at times in her final days mum was in pain and afraid. However she did not have the chance to express her wishes about her end of life care. We could only reflect back and think what this once vibrant, gentle and forever loving person would have wanted. She would have been most distressed knowing that her suffering was causing so much torment to others.

Mum's death taught us all that death is something to fear. We were denied lasting memories of shared tenderness, love and togetherness. Instead those last intimate moments have left us scarred with the bitter memories of mum's suffering. Mum had suffered her battle with MND so courageously and totally devoid of self pity. At the end she deserved a peaceful death one of which could only be ensured with human intervention. Tragically this was denied and as a result her cruel and unnecessary suffering will plague our lives forever.

By way of comparison, Lynda Shenton, diagnosed with MND, wrote to me in 2012:

> It has been twelve months since our paths crossed and I had the pleasure of meeting you to discuss end of life choices available to me. I have been living as normal and happy life as is possibly allowed with this insidious disease, and the anxiety I had before and after the diagnosis has completely disappeared since our discussion. I have been accepting of the fact that the change in my attitude to living without fear of being a burden is simply the fact that I can have control over my end when I decide it is not living any more but existing.
>
> This has offered immense relief, to me personally, as I feel it is a paramount requirement not being a burden on an energetic young family with new grandchildren to have to watch me suffer and have this on their minds and responsibility. No one benefits from such a struggle. In my mind I would not have been so confident of this before our discussion because I was totally preoccupied with the worry of being a burden not to mention everything that goes along with that situation which I can't even bear thinking about.
>
> I want you to know that I dedicate my well-being and calm happy life to your providing me with the information about medication when the time is right. You as a professional, compassionate human being have given me the life skill to live in completeness every minute of each day. I don't even think about what might or might not be, I just enjoy life.

Another MND sufferer wrote to me in 2013:

> Just a short note to thank you for our meeting last week to discuss my current situation with motor neurone disease. Your counselling and advice on how to manage the situation in the future was of great comfort and is most appreciated. It has left me with an understanding that I will be able to have some degree of control of events as they occur going forward. This has given me the ability to cope with my deteriorating condition with peace of mind and confidence to face the future. It is difficult to adequately convey my thanks to you—which is profoundly given.

These last two letters convey the sense of calm, and palliation of psychological and existential suffering, that an open discussion about the future, and the provision of advice and medication, provides. They illustrate the value of 'euthanasia talk'.

The wife of a man suffering from MND described his death as follows:

After hearing Dr Rodney Syme on 774 he rang and arranged to have a consultation with him.

George knew he had to be able to swallow and that was becoming more difficult. Toward the end of March he asked his family to come and see him for the last time. When they had all arrived he told them through strained breath that he thought he was going to die and that he loved them. George had wanted to stay and die at home and he knew the nurses wanted him to go into care as it was becoming very difficult for his wife as sole carer to look after him.

Everyone was having vegetable soup in the family room while George was having a sponge bath and changing into some clean pyjamas. His favourite music was playing loud in the house. He took a drink he had by the bed. He smiled at his wife and asked that the others come into the bedroom. George was propped up in the hospital bed with lots of pillows and the quilt his sister had made him. He smiled at the room full of his loved ones and closed his eyes.

'Over the Rainbow' was playing loud on the sound system. He went to sleep and didn't wake up. The palliative care nurse arrived an hour later and said how lucky he was to have such a beautiful passing. Everyone said they wanted to go like he did. Smile, close your eyes, and go. The family stayed all night and off and on went and sat with him. Talking and singing and crying. In the morning the funeral home came to collect him. The funeral was a fitting tribute to a man who had a full life and died with dignity in the loving embrace of his family.

The daughter of a retired farmer, Jim, also dying of MND, wrote about his death:

I can't explain how thrilled my father was to have control of his life again and how much it meant to him … When my father took the barbiturate we had encouraged him to sit on the bed and we made light of the fact that he should empty his bladder beforehand. Once he took the drug he slumped into a deep sleep and was actually dead within five minutes. The whole thing was very peaceful and he looked very relaxed and didn't appear to suffer. He was happy to the end.

Looking back on the day Dad ended his life, I can only say I have very happy feelings. Although there were mixed emotions at the time, I believe our memory of Dad's death is a lot easier to reflect on than if he'd progressed further with the illness.

Another letter describes the good death of a doctor. Through planning and good communication, he achieved his desired end—one that was peaceful for him, and left his family with warm memories:

My father, at nearly 93, frail and failing, had prepared himself well for his death: he had discussed his plans with his family, his three adult children; he had advised his GP, who gave his unqualified support and assurance that he would sign a death certificate even though ‘the immediate cause of death not be related to any current medical condition’ (Dad’s question to his GP!). His affairs and papers were all in order.

The day of his death his routine was as it had been for years, getting himself out of bed and dressed and into his favourite chair. He had his usual cup of coffee; he ate very little; he took Stemetil at regular intervals; in the evening, after announcing that he was ready, he had a glass of his favourite red, and without help got himself prepared for bed in his usual attentive way.

My sister and I had been with Dad all day. When he called us to come in we sat on the bed either side of him, with two prepared glasses, one of Nembutal and one of port. Dad took the glass of Nembutal, had a sip, then pronounced ‘you could acquire a taste for this with a little practice’, with a wry smile. He thanked us, saying ‘I couldn’t have done this without you, darlings’, then drank the rest of the fluid in two mouthfuls. The port was not touched.

Dad became drowsy within about 30 seconds, his respiration slowed and his head folded onto on my sister’s shoulder; together we lay him down in his bed, head on his pillow. His chest bumped a few times, there was some brief, deep sounds from his lungs that could have been distressing but his face was serene, and he didn’t move. It seemed not long before my sister said ‘he’s deeply unconscious and on the edge of death’.

We held him in silence for a while longer; and then my sister said ‘he’s gone’. I am uncertain of the time this took—it seemed only a few minutes to me, I want to say five; but it could have been 10 or 12. Not long. Next morning I called Dad’s GP early. He came, signed the death certificate C.O.A.D, and 2 days later Dad’s body was cremated.

Dad’s death was a happy one, and exactly as he wanted and planned: peaceful, serene, loving, absolutely in character for this man of calm independence and integrity, and an illustration of enduring dignity. In the nearly 7 years since his death my siblings and I have frequently reminisced about our father and his life. We miss him deeply and enduringly, but we do not grieve. He had a long and fulfilled life and his death was as he wanted. I know he died a happy man.

An end-of-life care roundtable, involving experts from Melbourne and Monash Universities and the Australian Centre for Health Research, made the following observations in its report:

Human quality of life up to and including end of life is extremely important to both the individual and their families. However, many Australians do not experience a good death …

> People are living longer and consequently the practice of medicine and the way we live and die has changed. Therapeutic and technical advances have improved and extended lives of many Australians, but at a cost. A new older generation of people is living with more complex disease and gradual decline in quality of life.
>
> There is an ongoing tension between principles of patient autonomy, which is desired by modern informed patients, versus medical paternalism.

It was also noted that the benefits of improving the system include ‘improved quality of life before death, maintenance of dignity, prevention of psychological burden and less likelihood of unexpected conflict and distress. Allowing time to “say goodbye” is critical’.

These observations align with those of the Australia21 roundtable on inequality in health and wealth, the Grattan Institute, and the report of the Victorian parliamentary inquiry. They all advocated change, and the reasons for it should be obvious by now: namely, the lack of effective laws protecting doctors regarding end-of-life medicine, and entrenched attitudes in certain powerful parts of the medical profession—principally the AMA, Palliative Care Australia and the Society of Palliative Medicine. (However, the AMA now represents only about 30 per cent of Australian doctors—hardly a ‘peak body’—and palliative medicine about 400 doctors.)

Analysis of the Grattan Institute criteria of what people want at the end of life makes it very clear that they cannot all be met under present circumstances. Currently, five of them can be met if people are determined and knowledgeable. While there is nothing to stop them asking their doctor to inform them truthfully about when death is coming and what to expect, they cannot control the adequacy of their doctor’s response. Similarly, they may have access to information and expertise but not necessarily all that they need. They can have access to spiritual and emotional support but may have to be proactive in seeking it. They can have access to hospice care but its availability

may be limited. They can issue advance directives (very soon to be legally protected in Victoria) but cannot be guaranteed that all doctors or institutions will honour them. They do not have control over the relief of pain and other symptoms—that remains firmly in the hands of their doctors, which has a huge impact on their being treated with dignity, on their terms.

Further, many people do not have control over where they die, or over who is present and shares the end of life. Both of these are intimately related to having control over what happens, including being able to leave when it is time to go, and being able to say goodbye. To achieve autonomy, you need control over when you die.

Many people reach a point when they are ‘ready to die’; when they are prepared and would not be distressed if death came to them. If death does not come, their suffering may increase so that they reach their ‘time to die’. They alone know when this point is reached. This may not coincide with their natural death, and it is in this space that incredible suffering can occur, and the medical profession inflicts great harm by failing to listen to their patients.

Too many doctors think that they know what is in the best interest of their patients. Bioethicist Daniel Sokol argues (*British Medical Journal*, 2008) that dying patients know best what is in their best interests. He asserts that ‘Overall best interests may legitimately differ from medical best interests, and the two should not be confused’.

A doctor is not a stellar presence imbued with power because of their knowledge. A doctor is not an agent in their own right. They exist only because sick people exist, and their role is to serve them via their knowledge. The doctor should bow down to them, not they to the doctor. The doctor must respect their patient’s autonomy. They must advise them, of course, as to what they consider the best medical action, but also recognise that such advice may not meet their patient’s considered needs and values. They need to

understand that providing control over the timing of dying, if rationally requested, is critical to a good death. That control may never be used, but is there anything that has greater value because it is not used? It provides profound peace of mind, something money can’t buy.

10

THE MOMENTUM FOR CHANGE

The public pronouncements of my involvement in Steve Guest's death were highly suggestive, but not explicit. The police interviewed me on two occasions, but I cautiously did not tell them exactly what I had given Steve, beyond saying blandly that it was 'medication that gave him control over the end of his life'. The publicity around Steve's death was significant, as both he and I had hoped it would be. While the drover's dog knew what I had done, this was apparently not enough for a prosecution to proceed.

I had hoped that the resultant publicity and discussion would enable legislation to be passed, but the Victorian Physician Assisted Dying Bill of 2008 failed, as did a series of bills in South Australia, Tasmania, Western Australia and New South Wales. Growing discouraged about legislative reform, I considered judicial options. I was mindful of the fact that Justice Menhennitt's ruling decriminalised the practice of abortion in Victoria in 1968, while the parliament's statutory confirmation took another forty years.

Perhaps the courts were the way to go. Moreover, a strategy of court challenges was leading to considerable progress in Canada. My medical colleague, and former Federal Minister of Health, Professor Peter Baume also thought the courts might be the way to go.

My own experience with police and coronial investigations, with the possibility of some Office of Public Prosecutions advice, had led me to the conclusion that there was a 'benign conspiracy' to avoid prosecutions for medical assistance in dying unless someone made a complaint. The Office of Public Prosecutions could justifiably say that prosecution of a doctor acting as I apparently was, with no public outcry, was not in the public interest, as it would have a deleterious effect on doctors' future provision of compassionate end-of-life care (as had happened in the United Kingdom with the prosecution of Harold Shipman, who was found guilty of the murder of fifteen elderly patients, but suspected of involvement in over 300 deaths). It would also open up for scrutiny the whole area of assisted dying by terminal sedation in palliative care, which was at least quasi-legal. Overlaying all that was my fundamental feeling that a jury, if asked to convict me in the matter of Steve Guest, would find that I was a good doctor, rather than a criminal.

I have, since the age of fifteen, when I first became aware of it through reading John Masefield's book *Gallipoli*, been deeply affected emotionally by the story of this campaign. Every Anzac Day, I am shredded by reflecting on the raw courage of those young Australians who fought there, and later on the Western Front. And since 2008, the question of why I could not 'come out of my trench' challenged me. I needed to 'find my voice'.

Finally, having, rather weakly, assessed that the risk was not very great, I told the media on 28 April 2014 that I had given Nembutal to Steve Guest. I had decided that I had such vast experience, possibly unique in Australia, of

assisted dying that I must talk about it. While I knew there was a high level of public support for change in this area, I also knew that many of the supporters were not well informed about the details and process of assisted dying—what actually happened.

I argued that I had not intended Steve end his own life—rather, I gave him the medication for the purpose of palliation; to provide him with control over the end of his life. Clearly I could foresee that he might use the drug to end his life, but that would be his intention, not mine. I drew a parallel with terminal sedation, where continuous medication was provided and it was foreseen that this could hasten death, but the doctor's intention was to palliate, or relieve suffering.

The outcome of my public admission was much as I expected. Six months later, there was a police interview in which a lovely sergeant told me I would probably not be prosecuted, because there was 'not enough evidence'. I do not know whether a brief of evidence was given to the Director of Public Prosecutions but, years later, I am still roaming around, being a nuisance.

Does my not being prosecuted prove anything? I think it gives some credence to my theory of a 'benign conspiracy'. I think it gives doctors who feel they have a necessity to assist their patients to die some confidence that, if they act conscientiously, and ethically, and consult with family to ensure everyone is on the same page, they are highly unlikely to be charged. Perhaps it also gives some credence to my defence of my intention to palliate. Unfortunately, though, it did not give rise to a judicial decision that would change medical practice in Victoria.

Since then, I have quite openly indicated I have given Nembutal to a number of people, including Peter Short, Ray Godbold and Albert Lorenzini, and acknowledged my promise to provide it to cancer sufferer Bernard Erica. Peter and Ray died naturally, while Albert, suffering from MND, did

take his medication in my presence. The result was silence, except, by accident, regarding Bernard.

In May 2015, I began a series of interviews with the amazing and influential Andrew Denton. He had been engaged to deliver the Di Gribble Argument annual lecture, sponsored by the Wheeler Centre, and he chose the topic ‘An Argument for Assisted Dying in Australia’. With his characteristic journalistic thoroughness, he interviewed many people in Australia, and then travelled to the Netherlands, Belgium, Switzerland, Oregon and Canada, to learn first-hand what occurred in these places, where assisted dying was practised lawfully. He subsequently arranged for me to appear on *Q&A,* and then on *Australian Story* with Bernard, who had contacted me in November after seeing me on *Q&A.*

Bernard had cancer of the throat, with a painful, malignant ulcer, and secondary cancer in his lungs. He had lost a considerable amount of weight and energy. I assessed that he would die within two months, as his treating doctors had indicated, and believed he would benefit enormously from having control over his end of life. I agreed to provide him with Nembutal when he was ready to die. He had already decided not to enter hospice care, and talked to his GP about ending his life. His doctor was sympathetic, indicating that he would sign a death certificate and not refer his death to the coroner. He remained fully supportive after Bernard advised him of his discussions with me.

Enter *Australian Story*. Unbeknown to me, the producer thought an interview with Bernard’s GP would be compelling, and persistently attempted to talk with him. The GP became alarmed at the possibility of his involvement with Bernard becoming public, and informed the Australian Health Practitioner Regulation Agency (AHPRA) what Bernard had said to him about me—he did not make a complaint. AHPRA then alerted the Medical Board of Australia. Within days, and without confirming the GP’s

statement with Bernard, the board decided I was ‘a serious risk’ to Bernard and to unnamed others in the community, and placed conditions on my licence to practise medicine. Bernard vehemently told the board I was no risk to him, and I appeared before the board and was quite frank about my activities and my reasons for them, but its decision prevailed. The matter is under appeal.

Meanwhile, when others learned of Bernard’s circumstances, and my dilemma, through *Australian Story*, he received two offers to provide him with Nembutal, so I have not had to. Nevertheless, I have continued to give him support, and, despite having no further cancer treatment, he is still alive, and mentally and socially active, at the time of writing. I like to think that his beating the odds in this way may be due, at least in part, to the palliative effect on his psyche of having control.

Law reform on abortion finally came about in Victoria following the government referring the matter to the Victorian Law Reform Commission (VLRC). The VLRC is a group of experienced and respected Victorians appointed by the government to investigate matters of legal significance and report on them to parliament. In view of the stalemate in parliament over law reform regarding assisted dying, DWDV agitated for it to be referred to the VLRC. Due to the energetic efforts of Greens Upper House member Colleen Hartland, debate on the referral finally occurred in early 2015. It concluded when the government leader in the Legislative Council, Gavin Jennings, proposed an alternative —referral of the question of end-of-life choice to the Legal and Social Affairs Committee. This proposal was carried and the committee commenced work within two months. After a year of investigation, it tabled a landmark report on 9 June 2016, concluding that the status quo in Victoria regarding end-of-life choice was unacceptable. It recommended to the government legislation for assisted dying (discussed further in Chapter 12).

A bill developed by the South Australian Voluntary Euthanasia Society (led by Frances Coombe) and Labor Member for Ashford Steph Key is before state parliament, and has the support of the premier and the leader of the opposition. Due to the indefatigable activist Margaret Sing, another bill is about to be introduced into the Tasmanian parliament. A private member's bill on assisted dying is being drafted for presentation in New South Wales. There is a whisper that Queenslanders are preparing the state's first bill on the subject; while the Western Australian landscape changed in late August 2016. A Perth GP, Alida Lancee, announced that she had provided a palliative injection to a woman with end-stage respiratory failure, which had resulted in her death. The woman had twice tried to commit suicide because of her suffering. While the police began an investigation for murder, the leader of the opposition, who could recognise suffering when it stared him in the face, announced that he would consider legislation for assisted dying if elected in the imminent election. Finally, and as a powerful support for all this activity, Andrew Denton has formed Go Gentle Australia, an advocacy group that provides professional expertise to the media and otherwise promotes the facts of assisted dying.

These are exciting times in Australia.

In the eight years since the publication of *A Good Death,* much has happened overseas. In those countries where assisted dying has become legal, intensive ongoing academic research and government assessment has consistently shown five important outcomes of this. First, there is strong, continuing community support; second, there is no evidence of abuse; third, no evidence of harm to 'vulnerable' groups; fourth, growth of palliative care, and significant acceptance of assisted dying within palliative care; and fifth, no evidence of the so-called 'slippery slope'.

And there is strong medical support for assisted dying—a recent study by Eva Bolt (*Journal of Medical Ethics*, 2015) reported that 85 per cent of Dutch doctors would consider helping a patient to die. Sixty per cent of respondents to the survey had actually assisted a patient to die.

In Oregon and Washington, the relevant state health departments produce annual reports of practice. The numbers of people taking advantage of assisted dying legislation has been surprisingly small, having slowly increased in Oregon, over about nineteen years, to 0.3 per cent of all deaths in 2014.

In Switzerland, there is no specific law allowing medically assisted dying, only one allowing assistance in suicide provided it is not for self-gain. There are no prescribed safeguards, but all such acts must be reported to the authorities. The Swiss government has found no need to intervene in these arrangements, and plebiscites of some Swiss cantons have strongly approved this situation. Prior to about 2000, Swiss medical bodies did not condone doctors' participation in assisted suicide, but this has changed rapidly. Thus, from a low base of 0.3 per cent in 2001, assisted dying increased to 1.1 per cent of all deaths in Switzerland in 2013. At the same time, deep continuous sedation (terminal sedation) has risen from 4.7 per cent in 2001 to 17.5 per cent in 2013.

Opponents of assisted dying frequently cite its increase as a worrying development. This seems to ignore the parallel rise, to a far greater degree, in terminal sedation. To me, the increase in assisted dying is totally expected, as more people, including doctors, become aware of the new laws and possibilities for a good death.

The increase has also been apparent in the Netherlands and Belgium, but has been slow and variable, depending on which year's data are chosen for comparison. The latest figures from the Netherlands are 2.8 per cent in 2010; and from Belgium, 4.6 per cent in 2013 (73 per cent of which

occurred in palliative care). The most significant changes in these countries have related to the circumstances in which assistance is given: namely, for minors, for people with psychiatric illnesses, and for people with dementia.

There has always been covert assistance with dying for babies born with severe, life-threatening malformations. This would occur after detailed dialogue with, and consent of, the parents. Often, however, death occurred after a prolonged period of non-treatment and, arguably, slow suffering. Dutch paediatricians explored this issue, and developed the Groningen Protocol, to provide carefully considered and humane assistance in dying. The Dutch government has accepted this protocol. In Belgium, after extensive public debate, parliament amended the law to allow assistance for minors. It is axiomatic that intolerable suffering is not confined to people aged over eighteen, and experienced paediatricians will acknowledge that children who have had prolonged treatment for severe chronic conditions can develop maturity in decision-making far beyond that of many adults who are without disease. They are capable of making rational and considered decisions about their own lives.

Increasingly, in both Holland and Belgium, doctors have been providing assistance to people with unbearable and enduring psychiatric suffering. This is not a covert extension of medical practice. The original legal criteria in each country had exactly this basis, of unbearable and enduring suffering, rather than terminal illness, as many people have assumed.

While most assisted dying in the early years of the practice was for people with terminal illnesses, more doctors have gradually come to understand better the realities of suffering, particularly in psychiatric illness. They have come to understand that there are some people with chronic psychiatric disorders who are beyond any effective treatment, and so have unbearable suffering, even though

they are not physically ill. Clearly, such decisions are the province of experts, and requires detailed and prolonged examination by psychiatrists, which is what happens. The inclusion of people with psychiatric illnesses in the framework of assistance is not evidence of a ‘slippery slope’—rather, it is evidence of gradual deeper understanding of the nature of suffering, and has taken place in broad daylight, with public discussion, and reporting of such deaths, to allow official scrutiny.

Dementia is a dreadful disease (in my opinion, the worst affliction known to humankind), which, unfortunately, causes its worst suffering when its victims are unable to make explicit decisions. Some people in the early stages of dementia may still be able to make explicit decisions, and have the experience, knowledge and imagination to be able to determine confidently that they do not want to make the full dementia journey. Dr Bolt’s research found that 40 per cent of Dutch doctors would help a person in the early stages of dementia to die, and 34 per cent would do this for a patient with a mental illness. Remember that, in every case, at least one other independent confirmatory opinion would be required.

In the United States, lawful assisted dying was extended from Oregon, to include Washington in 2008 (by a citizens initiated referendum), and Vermont in 2011 (by legislation). In Montana, there is no statutory prohibition on assisted suicide—this has been challenged in the courts, but remains law. In California, following failed referendums in the 1990s to allow euthanasia, a law on assisted suicide (‘aid in dying’) was passed in 2015, and Catholic governor Jerry Brown signed it into law. The California Medical Association abandoned its 30-year opposition to assisted dying, removing a major obstacle to the bill. The association’s president, Luther Cobb, said, ‘as physicians, we want to provide the best care possible for our patients. However, despite the remarkable medical breakthroughs we’ve made

and the world class hospice and palliative care we can provide, it isn't always enough'. Following the very public death, in November 2014, of Brittany Maynard, a 29-year-old woman with an inoperable brain tumour, community and legislative activity to achieve further law reform has exploded in the United States. Currently, 45 million Americans have the benefit of being able to talk lawfully to their doctor about assisted dying.

Meanwhile, the big mover has been Canada. There, progress has largely been through the courts. In British Columbia, in 2010, a case was brought before Supreme Court Justice Lynn Smith. The plaintiffs, Gloria Taylor (suffering from MND) and Kathleen Carter (suffering from spinal stenosis) argued that the Criminal Code violated their rights under the Canadian Charter of Rights and Freedoms, as it prevented them from obtaining assistance to die, which they would need, as they were disabled. They had a superb legal team, led by Joe Arvay, who prepared a most extensive brief of information gathered from around the world, to which I was privileged to contribute. It included a range of expertise from general medicine, palliative care, neurology, disability studies, gerontology, psychology, law, philosophy and bioethics.

The plaintiffs' argument convinced Justice Smith to declare that the provisions of the Criminal Code preventing physician assistance in dying violated disabled people's right not only to equality, but to life, liberty and security. As Joe Arvay said, her decision allowed for physician assistance in dying for any grievously and irremediably ill competent adult. Justice Smith proposed a 12-month suspension of her judgment to allow parliament to consider the matter, except in the case of Gloria Taylor, who would certainly not survive twelve months.

This decision was appealed, and the case eventually found its way to the Supreme Court of Canada, where it was

considered as *Carter v Canada (Attorney General)* (2015 SCC 5).

But before this case was considered, Bill 52 was put before the Quebec parliament, with the support of the junior health minister, Veronique Hivon. In Canada, the provinces regulate health and the federal parliament regulates crime (in contrast to Australia). The bill was to provide 'aid-in-dying', which was a medical procedure that doctors provided to patients on request, rather than assistance with suicide, which would involve a change to the criminal law. The complex Bill 52, allowing doctors to deliver lethal injections in very strict cirtcumstances, was passed and became operational in December 2015.

In February 2015, the Supreme Court heard the appeal, and ruled that the ban on physician-assisted dying violated the constitutional rights of grievously, irremediably ill people who were dealing with enduring suffering. This was a unanimous 9–0 decision, overturning the 1993 5–4 decision in *Rodriguez v British Columbia*. The court gave the federal government one year (until February 2016) to create legislation giving access to physician-assisted death, failing which the provision of assisted dying that met the court's criteria for eligibility would be ungovernable by the criminal law.

Subsequent to the Supreme Court decision, a large number of panels and inquiries was set up. A federal government panel, the Centre for Bioethics of University of Toronto, a provincial govern ments panel, a provincial–territorial expert advisory group, the Canadian Bar Association, the College of Physicians and Surgeons of Ontario, and the College of Physicians and Surgeons of New Brunswick all gave support to, and advice on, the development of the new law.

Justin Trudeau's Liberal Party defeated the Conservative Party in late 2015. Trudeau had given a commitment to legislate the Supreme Court's direction, but when legislation

was finally presented to the parliament, it was restricted to those who were terminally ill (whose death was ‘reasonably foreseeable’; not the broad description, of grievous and irremediable ill persons, the court had ordered). Parliament passed this limited legislation, after a proposed amendment for a broader provision (essentially, for advanced incurable illness) was defeated.

There is no doubt this legislation will be challenged in the Supreme Court in the near future. It is a typical political compromise, which does not deal with the problem, does not meet the Supreme Court’s clear directions, and excludes people with an advanced incurable illness, whom the court clearly supported. While a court challenge drags on, more people will suffer grievously.

The Canadian Medical Association (CMA) was proactive even before the Supreme Court decision. In 2014, it overturned its opposition to assisted dying, stating, ‘there are rare instances where patients have such a degree of suffering, even with access to palliative and end of life care, that they request medical aid in dying. In such a case, and within legal constraints, medical aid in dying may be appropriate’. In June 2015, a draft framework of rules for assisted dying was proposed, and at its AGM in August 2015 the CMA passed a resolution stating it ‘will advocate for the adoption of a framework for physician participation in medical aid in dying that is based on the principles of respect for patient autonomy, equity, respect for physician values, consent and capacity, clarity, dignity of life, protection of patients, accountability, solidarity and mutual respect’. I’ll vote for that!

The CMA then proceeded to develop guidelines for government on how such a resolution should be implemented in practice. In August 2016, it announced that heavily subscribed online information about medical assistance in dying was available. What an example in leadership for the AMA to follow.

It is very clear that there is rapidly growing momentum for change around the world. Australia, once a country noted for its leadership in social change, is lagging behind. It is time for our politicians, in whose hands this change lies, to become better informed, and better attuned to the mood of their constituents.

11

BILL AND MARY

Sometimes we learn as much from the partners of the dying as we do from those with incurable illnesses. I wrote about Bill in Chapter 4. He had a high spinal fracture with complete paraplegia and partial quadriplegia, had had his kidneys removed, and then developed crippling spinal pain due to failure of the metal rod in his back that supported the fracture. His wife Carolyne's incredibly brave recollection of their journey, as told in *The Saturday Paper*, has many more lessons to teach us.

Bill's courage, and that of many other, usually young, people who sustain a severe spinal injury, should be applauded. Life must begin anew after such an injury. Bill was fortunate that his career had been in academia, so he was able to return to that role, and continue to make a valuable contribution to society, as well as to his family.

No less courage, and tremendous devotion, was shown by Carolyne, who, despite Bill's rehabilitation, needed to

become his carer, particularly due to his kidney problems. She wrote:

> By the time of his decision, Bill had spent more than three years needing semi-regular nursing care at home. This was a role that was provided by me. It's not a role that people imagine when they get married, and certainly not a role most people in their 40s would embrace joyfully. We both felt, wordlessly, that Bill's illness and its complications had stolen from us a good part of our normal life as a couple.

So, as Bill's life had become highly medicalised, so had Carolyne's. Hospitalisations, complications, administration of drugs and interventions were frequent. As a urologist, I have removed both kidneys from a number of people with kidney failure or severe disease, and, no doubt, regarded the successful removal as a job well done. No doubt the renal physician providing the dialysis felt that his team was doing a very efficient job. Perhaps that was why he was astounded when Bill told him he was ceasing dialysis and the reason for it—his intolerable pain—and why the renal physician was resistant to Bill's decision. He saw Bill as a patient, not as a person, and could not see how his suffering afflicted the whole person. As Dr Eric Cassell said, doctors may fail to see suffering when it is staring them in the face. This is why I intensely dislike the word 'patient'; it has a habit of removing the person from the picture.

Although Bill had always seemed totally rational to the renal physician prior to his decision to cease dialysis, he insisted that Bill have a psychiatric assessment. This was not unreasonable, for, although Bill had a statutory right to refuse medical treatment, he needed to be mentally competent to make that decision. The psychiatrist, after an interview lasting ninety minutes, determined that Bill was 'of sound mind and not depressed'. Both the renal physician and the psychiatrist tried to convince him to alter his decision, and the renal physician insisted on another psychiatric assessment, by the hospital's head psychiatrist.

The lack of understanding and empathy from his doctors was sad, and Bill was having none of it.

As I read Carolyne's story, I was very upset to learn that Bill had been forced to make his decision alone—he apparently did not feel able to get advice from his doctors. Had he been able, he and Carolyne would have been better informed about the law regarding refusal of treatment, and about the palliative treatment he could expect. I was encouraged, though, by the subsequent support provided by his GP, who took the trouble to visit him every day, to allow him to die at home with good palliative nursing.

Carolyne's brave account describes her extreme emotional distress on hearing of Bill's decision. Ultimately, her realisation of his severe, unrelievable pain brought acceptance of his decision, and the support and sound advice of Bill's family was of great assistance. Being able to understand and share such a decision is critical to an acceptable outcome.

Carolyne's observations regarding Bill's decision and death are significant:

> In trying to understand more fully why Bill chose to do what he did, I came to realise the importance to us all of rational choice. After reading the works of researchers, such as Sheena Iyengar, examining the activity of human choice, I realised how much autonomous choice is an innate and very strong human trait. Faced with an ill and damaged physical body that would no longer permit what he saw as normal existence—for him or those close to him—Bill's choice to die was a form of self-determination and even power. But although it was a peaceful loving death, surrounded by those close to him, it was something he would not have chosen if he could have looked forward to even a remotely normal life.

Her final reflections are awe inspiring, and reflect the bittersweet nature of controlled dying. At the moment of Bill's death, she 'felt an ineffable sadness—one shouldn't have to die at 45. But I also felt a huge sense of relief that he was beyond pain, that he had slipped away so

comfortably, that we'd had this week together just the way he chose'.

Years later, while trying to write about Bill's death, she found these words by philosopher Friedrich Nietzsche, which described it perfectly:

> To die proudly when it is no longer possible to live proudly. Death freely chosen, death at the right time, brightly and cheerfully accomplished amid children and witnesses: then a real farewell is still possible, as the one who is taking leave is still there.

She concluded:

> And so it was with Bill's death—a deliberate but never a suicidal choice, made by the soundest of minds—about which there should be no conspiracy of silence. I'm telling Bill's story now because, as a society, we need to ensure our end-of-life practices do not violate the essential principles—that we claim to hold so dear—of autonomy and self-determination.

Bill's story is of self-chosen death by refusal of treatment. Charles tells a similar story, except that his mother, Mary, chose to end her life with medication.

Mary, who was eighty, had been diagnosed with ovarian cancer in 2012. By September 2013, her doctors told her there was no further effective treatment and that her prognosis was three months or less. She asked Charles, who lived in Melbourne, to explore options for control of her end of life. He contacted me, and told me of his mother's circumstances. I explained how her disease was likely to proceed, so that she would have adequate information for decision-making. Interestingly, Charles's father was a respected physician, but he had no idea of his wife's intentions, nor any knowledge of how to help her. Charles wrote:

> She knew that her passing would leave a large enough hole in his life, and he didn't need the burden of being directly involved in her death. So you find from the very onset, not for all, but some, it's easier to tell half-truths and hope in the end that practicality prevails, everybody becomes aware of

> the situation, but in tacit agreement you don't acknowledge it. How can you? The law doesn't allow it and there are those in society who deem it a mortal sin and crime. Why should the easing of suffering be of any harm to anyone? To them it's not harm, but calm. It's the peace of knowing that you are finally in control. This is robbed from us; you have to be furtive, you have to pretend that things are other than they are. Surely at the end of one's life you should be given the freedom to drop pretence of society and its often draconian mores that are placed on us … Death is hard enough without having guilt being thrown into the bargain.

I told Charles that I would have to deal directly with his mother, and suggested that she call me if she wanted to talk. She lived in the north of Sydney and I was in Melbourne, but she did ring me and we talked for over an hour. She was suffering from abdominal pain, loss of appetite and weakness, and was later to develop ascites (a common reaction to ovarian cancer). Our conversation left me in no doubt she was terminally ill; was experiencing significant suffering, though was not ready to die; and that she was mentally competent. I encouraged her to engage in dialogue with her family. Since I was sure she would find effective palliation from having control over the end of her life, I then met Charles in Melbourne and gave him Nembutal, which he took to New South Wales, for his mother.

He wrote:

> On a December morning, I met Dr Syme and found him personable, confident, caring and intelligent in his discourse. I flew to Sydney that afternoon with medication to spend a final Christmas with my mother and family, with a sense of calm despite the morning's difficult nature.
>
> Fortunately my mother far outlived the doctor's expectations by almost five months. I could see the peace of mind it brought her, knowing she would not have to abide the consistent chronic pain and suffering that intensifies towards the end. Instead she could make the most of what she had left.
>
> How do you decide when the time comes? Mum's decision was made when she had lost her quality of life. Once your stomach starts filling up with fluid that needs to be drained every 4–5 days just so you can feel comfortable to suffer in silence, when you can no longer leave your house without help, when you can no longer be in your garden, go and see friends when your life grows so small that all it revolves is your bed and moving a

few metres to the couch, when you get brief moments, flashes of normal existence, before the weariness of the disease once more takes hold of your body. When you become a listless husk, when food and water is expelled almost immediately from your body and you are literally killing time, just waiting for the excruciating end. Visits by family and friends from the far sides of the world created a glorious and treasured time for her, helped her to find succour and peace of mind, more so because she had a plan and knew ultimately that she was in control.

Clearly, Mary did not give up easily. In April 2014, she gathered her family together for a day of love, music and remembrance. As she prepared to take her medication, there were moments of anxiety that, I am sure, could have been dealt with if I'd been able to be present.

So Mum drained her medication, and then quickly changing glasses to appreciate her last whisky, told a little joke about the bitterness and described the numbing feeling that was taking over her body, mentioning the sensation of how the back of her lips and tongue were feeling pleasantly numb. Her eyes closed and her last words turned to a drowsy mumble as she slipped into a very peaceful coma after only two minutes. I spoke to her about some of the wonderful things she had achieved in her life, as I wanted her to know that up to her last breath she was so loved and deeply cared for and respected. I don't know if she could hear me whilst I talked and the music played and we waited for her heart to stop, which seemed like an eternity, but in reality was less than five minutes from the time she drank her first sip. And she drank, there was no hesitation, this was something she had thought so much about, that she wanted and was accepting of. This was the point in time that she knew she would reach; even by her own admission that if it was not this way then certainly the stockpile of various medications she had secretly been squirreling away and hiding so that she could take a massive overdose, which has no guarantee of working and may in fact be long, protracted and agonising. This is no option for anyone, to take a cocktail hoping to induce death, which could have had horrifying consequences and not delivered the peace she so desperately wanted.

If I hadn't contacted Rodney Syme, Mum's death would have been protracted, painful and distressing, not only to her, but to us all. I would have lived a lifetime of regret if I was not able to ease her suffering. My mother passed peacefully and happily. Happy to leave the pain behind, happy to not have to face the daily suffering and excruciating pain as her body broke down, while her mind was still active and coherent.

Both Bill and Mary, in their different ways, faced futures of pain and suffering. They dealt with this in different ways,

but there were common threads. They both thought very deeply about their problem, reached firm conclusions about ending their lives and brought their families into those discussions. They ended their lives in different ways but, again, there were common threads. They died peacefully and with dignity, in the company of their families, after saying powerful goodbyes. They were both ready to die and had reached their time to die. A lack of choice did not extend their suffering. Each prepared for their death; each died in their own bed after saying goodbye to their family. These were deaths that, as Michael Barbato said, ‘we in palliative care hope to see but rarely do’.

12

THE FUTURE

What needs to be done in Australia to ensure a good death is possible for all?

It is essential to develop effective communication between people with terminal illnesses and advanced incurable illnesses, and those of advanced years who may well face mortality in the near future, and their families and doctors. No matter what changes occur in palliative care, or in the law surrounding assisted dying, problems will continue unless patients, their families and their doctors engage in honest, open communication about their suffering and what they want at the end of life. It is critical that all adults have a medical treatment decision-maker; there is no knowing when a crisis, due to trauma or disease, may strike even a twenty year old. For older people, and anyone with a serious disease, an advance care directive is an essential protection against unwanted treatment. The Grattan Institute recommended 'trigger points' for mandatory discussions during health assessments for

people aged over seventy-five years; for all residents of aged care facilities and for high-needs recipients of home-based care packages, as part of assessment and care planning; and for all hospital in-patients who are likely to die in the next twelve months.

Australia already has an exceptionally high standard of palliative care services. The Economist Intelligence Unit commissioned a report called the *Quality of Death Index*, which was a survey of palliative care services around the world, and found that Australia ranked second. Notably, however, the survey was based on the views of palliative care experts—the judges were judging themselves. On the basis of this report, highly respected Australian physician Professor Stephen Leeder wrote in the *Medical Journal of Australia*'s *InSight* (30 November 2015), in a piece called 'Dying Well', that Australia was the second-best place in the world to die. With great respect, it being the second-best place to die does not justify the contention that its people are dying well. Dying well for Australians, as the Grattan Institute report indicates, requires dying people to have choices about, and control over, the end of their lives.

Palliative care is a vital cog in the process of dying well and should be available to every Australian. It needs to be well funded, and to be available more effectively to people dying in their homes, and to people dying in nursing homes. I deliberately use the phrase 'nursing home' here, rather than the modern euphemism 'aged care institution', to remind readers that these places are not like home, and have very minimal nursing care. Nevertheless, they are where 32 per cent of people die. They are places ranging, in Professor John Bradshaw's words, from 'the splendid to the execrable', where GP visits are rationed, where support for dying patients is so limited that referral to hospital in a crisis is standard, with all the consequences that follow, such as unwanted investigation and treatment.

Again, palliative care needs to be well funded, and widely available. But we need better palliative care, not just more of the same. For this to happen, there needs to be a massive emphasis in medical education, at both undergraduate and postgraduate level, on the care of dying patients and on the relevant law. Make no mistake, the problem lies with the medical component of palliative care. You will rarely hear any complaint about palliative care nursing.

Better education includes education on communication with patients, not only in relation to dying people but generally. Good communication is an essential medical skill. I graduated reasonably well versed in medical knowledge, but only able to talk about it on a rather technical level. I spent two years learning some arcane anatomy, when three months of tuition in communication would have been more beneficial.

If good palliative care is to expand, it needs to spread to wider medical practice. Unfortunately, palliative care has contracted into a specialty, with the result that fewer and fewer doctors feel capable of, and confident in, dealing with dying patients, and are inclined to handball these problems to others.

While I endorse the expansion of palliative care, I do not accept it expanding into a monolithic organisation that determines how people die—the palliative care way or the highway. Palliative Care Australia has acknowledged that it cannot, even with optimal care, relieve all the pain and distress of dying people. Since 2006, its position statements on euthanasia and assisted suicide have gone backwards, becoming more obscure and exclusive of broad opinion. (Dr Alastair Bonnin describes this process of withdrawal in Chapter 6.)

What is Palliative Care Australia's solution for people with refractory suffering? It is terminal sedation; refusal of treatment (if that is, in fact, an option); or ceasing to eat or drink (rarely, I think, suggested in Australia). I would argue

that these are not ethically acceptable as the only options, and not acceptable in a practical sense to many people. But with palliative care as the only available port in a storm, what other options do people have?

Palliative care functions on the basis of both not hastening death and relieving suffering. These are both goods. Sometimes these principles come into conflict—when suffering will only end with death, there is a necessity therefore to hasten death. The suffering person's view should guide the decision about which good is more important—for many, the relief of suffering is the greater good. The hastening of death need not be intentional, but can occur by the administration of medications that fully relieve that suffering. Even though the likelihood of hastening death is foreseeable, such action is not illegal, and the AMA and most bioethicists regarded it as ethical. However, it seems that the usual palliative care practice is to err on the side of not hastening death, rather than effectively relieving suffering. Hence, there is terminal sedation by slow titration, with the consequences of slow and only partial relief of suffering until unconsciousness ensues, and an often prolonged period of unconsciousness. Many people would find this unacceptable, unaware that it may await them.

And there is another ethical conflict in palliative care—between sanctity of life and autonomy. These are also both goods, but can clash at the end of life. The Supreme Court of New South Wales (*Hunter and New England Area Health Service v A* [2009] NSWSC 761) referred to Lord Goff's statement in the House of Lords decision *Airedale NHS Trust v Bland* ([1993] 2 WLR 316) that 'the principle of sanctity of life must yield to the principle of self-determination'.

There don't have to be such conflicts. I know of a palliative care physician who provided sedation to a woman with MND, so that she went to sleep quickly and died at home within forty-eight hours. Such care is ethical and

legal, but seems to be unusual, due to the prevailing culture of palliative care. An approach that involves open discussion between patient and physician, and agreement on terminal sedation with doses of medication that will properly relieve suffering from the outset, even if such medication has the foreseeable but unintended effect of hastening death, would enhance palliative care's acceptance in the community.

It is my view that when an assisted dying law is passed, it would be best for assistance to occur within a palliative care framework. That way, people could get the very best palliative care, but if they reached a point where their suffering was no longer being controlled, they could say, 'Thank you for your care,' and request assistance with an early death. However, this is almost certainly not going to happen without a significant change in palliative care culture. If palliative care continues to oppose assisted dying, it should make that clear so that patients can begin communication with other doctors. Palliative care could also contemplate the value of 'euthanasia talk' as a palliative tool.

Some in palliative care are fearful of an erosion of trust in medicine generally, and palliative care in particular, if assisted dying laws are passed. Professor Ian Maddocks does not share that view (*InSight*, *Medical Journal of Australia*):

> I do not fear an erosion of trust if assisting dying under clearly defined circumstances is decriminalised, rather it might increase patient trust. I think of two instances where single aged female patients with terminal cancer died suddenly and unexpectedly at home. I felt sure that they had taken accumulated analgesia/sedatives. My regret was that they had not been able to share the decision to do that with me, and I was not able to ensure that no disaster of half-death occurred. When I can sit with patient and family through the last hours it is a moving and very comfortable experience for us all. These women had to deny that opportunity for themselves, their loved ones and me.

Assisted dying is not a threat to palliative care, as shown by evidence from overseas. They are integrated in Belgium,

occurring by patient choice within the same system. Palliative care has grown markedly in the Netherlands, side by side with euthanasia, and Oregon has among the highest usage of palliative care in the United States. More than 80 per cent of people in Oregon who legally obtain oral barbiturates are in hospice. Helene Starks and colleagues studied (*Journal of Pain and Symptom Management*, 2005) the circumstances of thirty-five Oregonians who had requested a hastened death. They commented:

> Most experienced a kind of existential suffering that wasn't related to a transcendental fear of dying, or fear of punishment by their god … Attitudes to terminal sedation were discussed—most felt it would only prolong the dying process, and increase the burden on family members.
>
> The Oregonian Hospice Association and Oregon's hospice community respect Oregonians' right to choose. Oregonians need to know, however, what their choices are. In public debates over physician assisted suicide, opposing alternatives are often offered—'suffer or die. Hospice or physician assisted suicide'. But no Oregonian must suffer and no Oregonian must choose between hospice and physician assisted suicide. A dying Oregonian can choose both from among the options on the end-of-life continuum of care—Oregon's hospices support patient choice.

Legislation for assisted dying does not harm palliative care—these two approaches are not in competition with one another, but should be complementary if best practice is followed. Unfortunately, Australia will not have best practice even if assisted dying laws are passed, unless palliative care comes on board and accepts such changes for the benefit of its patients.

Once again I quote Professor Michael Ashby, one of the most balanced voices in palliative care (*QUT Law Review*, 2016): 'Palliative care needs to be available to all, regardless of belief about assisted dying, but it also needs to be acknowledged that palliative care, however good and available, does not meet the needs or autonomous wishes of all people'.

The Victorian parliamentary committee concluded in June 2016 that the status quo regarding end-of-life matters was

unacceptable. It strongly recommended that the government introduce legislation for assisted dying, with strict conditions, which it outlined. This report was extremely comprehensive, with the inquiry having taken submissions from nearly 1000 Victorians, and visited the Netherlands, Switzerland, Oregon and Canada to obtain first-hand evidence of how the laws operated there. Notably, the Victorian coroner's submission was influential. Evidence was presented that Victorians with life-threatening or severe chronic illnesses were ending their lives by violent means once a week on average, and the conclusion was that they could not obtain medical treatment or advice. Nearly 60 per cent of these unfortunate people had a chronic condition and were not terminally ill.

Despite this evidence, the inquiry recommended that the government legislate to allow only people with 'weeks or months to live' to request assistance (that is, the terminally ill, similarly to the Oregon legislation's qualification). This recommendation conflicts with the coroner's submission, and has the potential to exclude many people suffering severely—for example, from MND, MS, Parkinson's disease, profound permanent stroke, high quadriplegia, and chronic heart, respiratory, kidney and liver failure. These people all have advanced incurable illnesses, and suffering that is severe because of its chronicity and the extended time for which it may persist. To place a limit on requests based on the anticipated time to death is not sensible, as such judgments by doctors are acknowledged to be highly uncertain. A typical result would be that a doctor dealing with someone they judge to have intolerable suffering but with no clear prognosis regarding death would either have to deny their patient or fudge the law. Neither outcome should be encouraged in a decent, law-abiding society.

So, although the passage of legislation allowing medical assistance with dying for suffering people with 'weeks or months to live' would be a welcome development, it is a

compromise, which will fail because it only addresses part of the problem. All those people with advanced incurable illness will be excluded, and the majority of the type of violent suicides the Victorian coroner cited will continue because these unfortunate people will not qualify for assistance under this restriction. My counselling data clearly indicate that a significant number of requests for assistance come from people whom this proposed model would not include. People with advanced incurable illnesses will still approach doctors, who will either have to say no or break the law. I have no doubt that covert assistance with dying would continue under such a restrictive law.

The Canadian Supreme Court unequivocally determined that assistance should be available for those people who were ‘grievously and irremediably ill’, and yet the Canadian parliament passed a bill allowing assistance only for those for whom death was ‘reasonably foreseeable’. Kathleen Carter, in whose name the Supreme Court challenge was made, would not have qualified for assistance under the new law! A grievous mistake by parliament but not, fortunately, irremediable. There will undoubtedly be another Supreme Court challenge by someone with an advanced incurable illness; however, further suffering, and a waste of time and money, will have occurred.

The South Australian Consent to Medical Treatment and Palliative Care Act 1995 defines terminal illness as ‘an illness or condition that is likely to result in death’, and the terminal phase of a terminal illness as ‘the phase of an illness reached when there is no real prospect of recovery or remission of symptoms, on either a temporary or permanent basis’. This definition has never been challenged as unsatisfactory.

A person in the ‘terminal phase of a terminal illness’ can be seen as on a defined pathway to death, and would be covered by the Victorian parliamentary inquiry’s limit of ‘weeks or months’ to live. Such people may have a

depressed mood as a result of their circumstances, and the evidence shows that psychiatric treatment cannot alter this depressed mood. There is no point—indeed, it is an insult—to suggest that such people, except in rare circumstances, undergo a mandatory psychiatric assessment of their competence to make decisions. People with an advanced incurable illness have usually been suffering from it for a considerable time. Due to a lack of any improvement over such a period, these people are highly likely to be clinically depressed. Many have been diagnosed and treated as such, usually with little success, because if you cannot alter the circumstances causing the depression, you cannot resolve the depression. It is reactive, an adjustment disorder. Nevertheless, in the circumstances of advanced incurable illness, I accept and recommend that a psychiatric assessment and consideration of a trial of treatment be contemplated, if this has not already occurred.

The second major difference between people in the terminal phase of a terminal illness and those with an advanced incurable illness is the timeframe until death. For the former, it may be weeks or months; for the latter, possibly years. There is, indeed, a need for extreme caution, and patience, in assessing the merits of a request for assistance from someone with an advanced incurable illness. But there is also a huge benefit in opening the door to a discussion about the possibility of assistance. These people have often been dealing with doctors who keep that door firmly shut, and who do not show respect for the depth of their suffering (admittedly, often because it has never been clearly expressed). When these people approach me for counselling, I tell them to let their treating doctors know that the level of their suffering is driving them to consider ending their lives. Often their doctor has been unaware of this but, as a result of finding out, increases their efforts to find solutions. Frequently I don’t hear from that person again. This may be because I have disappointed them,

although I always offer further contact if things do not improve for them. On the other hand, it may be because a solution has been found.

Being prepared to listen, to show empathy, and to promise further dialogue in the future, if necessary, has a profound palliative effect. The Swiss organisation Dignitas has observed the same phenomenon—giving someone the ‘green light’ for future assistance frequently results in that person ultimately dying naturally. Dignitas claims, based on sound evidence, that its services have, in a practical sense, a suicide-prevention effect. (Frances Norwood’s research on ‘euthanasia talk’ comes to the same conclusion.) A number of people I counselled and to whom I gave medication either never used it, or went on with their lives far longer than I would have thought possible.

Throughout this book, I have used the phrases a‘completed life’, of being ‘ready to die’ and a ‘time to die’. They are all concepts that have come to me through my counselling work. Many people who have lived a satisfying, long life but are now facing a terminal illness, or a frail future, probably confined to institutional care, will agree that they have a ‘completed life’. They have nothing more to achieve; in fact, there is nothing more they are able to achieve. They are ‘ready to die’, and the time that elapses until they finally die may be painful in the widest sense. Eventually, that pain or suffering may reach a point they consider their ‘time to die’ has been reached. They are no longer merely waiting to die but are actively seeking to die. From this point, their suffering until they die is intense. It is people in this group who not infrequently make requests for assistance. While they may not actually be dying, they are enduring great suffering and there should be no discrimination against them.

The Victorian parliamentary inquiry report (9 June 2016) concluded that there is a ‘remarkable degree of leniency shown to offenders [in “mercy killing” or assisting another to

die], even though there is a clear violation of the criminal law’; nobody prosecuted in Victoria for assisted dying has received a custodial sentence. It continues: ‘While the outcome may appear just on a case-by-case basis, the reliance on individual discretion to achieve just outcomes rather than the systematic implementation of the law threatens to undermine public confidence in the administration of justice and bring the law into disrepute’. It went on to say, ‘The widely acknowledged fact that members of the medical profession are known to be breaching the law but avoid prosecution may threaten to undermine public confidence in the administration of justice and bring the law into disrepute. It also shows that those in authority do not believe that justice would be served by robust application of the law as it stands’. So, the committee found a serious discrepancy between the law as it stands and as it is applied in practice. This raises the question of whether the law reflects the Australian community’s contemporary values. The inquiry found that ‘the current legal framework is not serving Victorians well’; rejected maintaining the status quo, as a ‘head-in-the-sand approach’; and strongly recommended that the government legislate for assisted dying. In reaching this conclusion, it stated that ‘concerns raised in arguments against assisted dying—such as the inability to implement and maintain effective safeguards—have not eventuated in jurisdictions where assisted dying is legal’. The report added, ‘While concerns about the safety of vulnerable people and the need for them to be protected are valid and should inform the design of any assisted dying framework, the Committee did not find evidence to support these concerns’. Moreover, it pointed out that Victoria’s existing legal framework does not adequately protect vulnerable people.

The inquiry received a strong submission from physician and ethicist Paul Komesaroff and retired Victorian Supreme Court of Appeal judge Stephen Charles. They argued for

limited reform of the Crimes Act 1958, to allow a defence for doctors to a charge of homicide or manslaughter if the doctor prescribed or administered a drug that hastened or caused the death of a patient with a terminal disease. This defence would apply if the doctor reasonably believed that it was necessary to prescribe or administer the drug to relieve a patient's pain and suffering; or prescribed or administered the drug with the intention of relieving such pain or suffering. This idea has some value, as it would validate in statute law much current covert medical end-of-life practice—if you protect the doctor, they are better able to help the patient. But it has three problems: first, it keeps all the control with the doctor, giving no right to the patient to request medication; second, it provides no defence against a charge of aiding and abetting suicide; and, third, it depends on the doctor following accepted medical practice. This last concept is tricky—since the proposed protected actions have hitherto been hidden, there is no 'accepted practice', and if there were one, how would it change to allow for more compassionate acts?

The inquiry finally proposed an assisted dying framework. Based on an amalgam of existing successful laws in overseas jurisdictions, it determined that access to assisted dying not be a 'right'. Instead, access would be determined through careful assessment, according to a robust set of criteria, by those best placed to do so: the person themselves, a primary doctor and an independent secondary doctor. Finally, the report stated that 'the needs of the patient must be squarely at the centre of an effective framework', and that 'it is not for others to decide what is tolerable for a patient'.

The inquiry recommended that access to assisted dying should only be available to, first, people suffering from a serious and incurable condition causing enduring and unbearable suffering that can't be relieved in a manner the

patient finds tolerable; and, second, to people in the final weeks or months of life.

This second condition is the one aspect of the inquiry's recommendations with which I disagree. The entry point of 'unbearable and enduring suffering', experienced by the patient and confirmed by the doctor, is central to the Dutch and Belgian legislation. This is logical because suffering, not any specific illness or length of time to end of life, is the critical issue. In contrast, the 'end of life' restriction is central to the Oregon legislation entry criterion (with terminal illness meaning less than six months to live). Again, people with an advanced incurable illness would be excluded, which would be the cruellest discrimination and would not resolve a fundamental problem.

The remaining recommendations for the legislative framework were all based on the law as it has been seen to operate effectively in many overseas jurisdictions. These safeguards included an assessment of suffering and review of possible further treatment; consideration of state of mind regarding competence, with referral to a psychiatrist if in doubt (but this is not mandatory); consideration of informed consent, and provision of appropriate information regarding palliative care; consideration that the request is enduring, well considered and not a spur-of-the-moment decision; confirmation of all of the above by a second independent doctor; and a requirement for separate written and oral requests for assistance. There was no requirement for a specified mandatory waiting period between requests. There was protection for health professionals who refused involvement in such assistance. There was to be mandatory reporting of assistance, and regular reviews of process by statutory panels. There was to be funding for research, review and recommendations for changes in, or development of, the law.

One recommendation in particular pleased me, and demonstrated the committee's depth of research and

insight—that assistance should be by providing medication for personal administration by the suffering person. This is a profound safeguard. Administration by other means (for example, by injection) would only be allowable if self-administration were not possible. This is similar to a recommendation of the Royal Dutch Medical Association in 2009.

One topic the inquiry did not address but that needs to be resolved is the intense community fear of being charged with a criminal offence—of assisting in suicide—if they are present when a dying person ends their own life. The consequence of this fear is that many people have to die alone, and their families suffer extreme grief and guilt because of their apparent lack of support. But the reality is quite different. Detective Inspector Mick Hughes of Victoria Police told the inquiry, 'you almost need to be in the same room with the person, *encouraging, inciting or taking part*' for a charge to be laid. Queensland Police Chief Commissioner Bob Atkinson said, after an inquiry into Nancy Crick's suicide (where twenty-one other people were present), that 'being present when someone takes their own life does not of itself constitute a criminal offence'. A clear statement by the police or the Director of Public Prosecutions could readily eliminate this community fear.

It will be intriguing to observe the change in palliative care when legislation for assisted dying is passed. I predict that, despite an initial outcry, there will be a gradual revision of attitude and practice, as happened in Oregon. There are already a number of palliative care physicians who support change, as, more particularly, do nurses, causing pressure to build. In addition, pressure must come from their patients who want access to assisted dying. It will be difficult for palliative care to maintain stringent opposition if it wants to maintain the trust of the people. In my view, legalised assisted dying will not damage palliative care

unless palliative care makes the mistake of adamantly opposing it.

Jerry Brown, Governor of California and a committed Catholic, who had trained as a Jesuit, had the right to veto the assisted dying bill his parliament passed. Instead, in a very rational and compassionate letter, he concluded:

> In the end, I was left to reflect on what I would want in the face of my own death. I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others.

Many working in palliative care probably feel the same way.

I have enunciated six 'medical givens', or self-evident truths, regarding end-of-life circumstances, and the arguments this book puts forward enhance their validity. There is no argument that dying can be associated with significant suffering, which may escalate as death approaches. There is no argument that sometimes such suffering will only end with death, and that the best palliative care cannot relieve all such pain and suffering. There is no argument that rational suffering people persistently request assistance to die, that medical ethics and the law support their autonomy to make such requests, and that doctors have a duty to respect such requests. It is a doctor's historical role to relieve suffering, even at the risk of hastening death and especially if their patient requests them to do so. These truths, the bedrock upon which the argument for assisted dying rests, underlie the Victorian parliamentary inquiry's recommendations.

Soundly constructed polls (such as Roy Morgan and Newspoll) show that 75–85 per cent of Australians support legislation for assisted dying, this support having

progressively increased over twenty years. However, only a small fraction of these people do anything to effect this change. Social change ultimately comes through the political process but not without community pressure. Comte de Mirabeau wrote at the time of the French Revolution, ‘Man responds to impressions rather than reasoning … [he] has to be moved rather than convinced’ and this is probably true today. I hope this book will not only provide the reasons for change but create the emotions for change—inspire ordinary people with a concern for humanity, or even just their own future, to engage with their elected representatives and demand assisted dying laws be passed.

Many dying people would prefer complete relief of suffering, rather than partial or intermittent relief of suffering, even if this would result in hastening of death. Some of them insist on having more choice. Ending your life is the most autonomous action a person can make. If such an act is irrational, or inconsistent with a reasonable analysis of the situation, or avoidable with compassionate endeavour, everything should be done to avoid it. However, if death is inevitable, if life is being plagued by gross, unrelievable suffering, a decision to end that suffering may be entirely rational. If so, such a decision should be humanely supported, shared by friends and relatives, and the end occur with dignity, security, peace and love.

POSTSCRIPT

As a result of my prolonged contact with dying people, and people exploring how their life will end, I have developed some eccentric attitudes to cultural norms.

Two of my illustrious forbears are buried in large cemeteries in the Melbourne area. They have major stone monuments above their graves, which once held coffins containing their bodies but would now contain dust. As Ecclesiastes says (3.20), ‘All go to one place: all are from dust, and all will go to dust’. I have never visited these gravesites, and have no inclination to do so. I am well aware of my forbears’ achievements, which exist in my mind, not in a stone memorial.

Burial with a memorial has been a central part of human history, wrapped in the mystery, and the hope, of rebirth. In Christian mythology, the idea of a Doomsday or Day of Judgment to come, when graves would burst open and all good souls ascend to heaven, gave succour to people in times filled with poverty, famine, misery and despair. Although the modern world is still full of these phenomena, the idea of limbo is vanishing fast, at least in the western world. Nevertheless, the culture of burial with a memorial

remains, even among those who hold no significant religious belief and often at great cost.

Although cremation has been practised from the earliest historical record, it was banned by the Christian Church, and strictly forbidden in the Middle Ages, on the basis that it prevented the resurrection of the body. A movement to allow cremation began in the United Kingdom in 1870, leading the Archbishop of London to say that cremation would ‘undermine the faith of mankind in the resurrection of the body, and so bring about a most disastrous social revolution’. He may have been right in his first assumption, but we are still waiting anxiously for the second. Theologians have made much the same sort of comments about the legalisation of assisted dying. Catholic canon law banned cremation in 1917, although it was noted that there was no scriptural basis for the ban. In 1963, the Catholic Church lifted its ban on cremation, but its 1983 canon law still favoured burial.

Both of my parents were cremated. I cannot remember where their ashes were scattered; it was probably in their garden (my mother’s nickname was ‘Gardy’, for she loved her garden). But this doesn’t matter—memories of them are deep in my mind, not located in any particular physical place. They don’t need a memorial to continue to inspire me, and for me to think of them, which happens frequently.

The funeral rite as a method of remembrance and farewell is an ancient tradition. However, with the advent of Christianity, it developed a religious context, and in countries that have a Christian background it traditionally takes place in a church or chapel. Today, as a matter of convenience, many funeral services (now often thought of as commemorations), even for non-believers, still take place in religious institutions. From my first acquaintance with such a service, I felt alienated by the religiosity. But two other aspects also disturbed me. First, the strain placed on the bereaved’s spouse and family in having to appear with a

brave face so soon after their bereavement, in order to meet a cultural requirement, struck me as cruel. Second, there was the fact that many people gathered to show their respects, and share their experiences, regarding a central figure who was not there to participate.

Having shared some farewells of people who were making a planned departure from life, I have been intensely moved by the sharing of joy and love when people meet to say goodbye to someone they know well and respect. The dying person is present at their own wake, can share the laughter and the jokes, hear and contribute to the stories in all their candidness. These are not grim affairs—far from it. There is a certain sadness, yes, but coloured by an understanding that we will all die, and an acceptance that the right moment has been reached to say goodbye. Too often, people die without acknowledging what others have meant to them and what they have meant to these others.

I feel no need for a funeral, no need for a burial—these are the hallmarks of a disappearing culture. I want, if I have the chance, to share the end of my life with those people who have been important to me, to say goodbye, then die peacefully in the company of my family, and have my ashes scattered to the wind, I don't care where. Again as Ecclesiastes says (3.2), there is *'a time to be born and a time to die'.*

I want my dying to be a positive farewell to life—a statement rather than an apology; a climax rather than a damp squib; a celebration, rather than something confronting, for those I love. To have the chance to die as I would like, I will need to have control over it. As a doctor, I have that, but everyone should have that same choice.

WITH RESPECT AND GRATITUDE

Many people have shared their stories of pain and suffering, fear and distress with me.

I thank them for having the courage and the confidence to do so. They have taught me what I now know about the complexities of making decisions at the end of life.

They have helped me to learn how dying can be a rewarding experience for people who are open to preparing for, communicating about, and sharing that experience with those they love.

My family, and friends and colleagues at Dying with Dignity Victoria, have given me incredible support in my journey.

I thank Sally Heath, Sarina Rowell and Cathy Smith of MUP for turning my ideas into a readable document.

BIBLIOGRAPHY

Ahmedzai, S., 'My journey from anti to pro assisted dying', *British Medical Journal*, 2012: 345; 4592

Ashby, M., 'Hard cases, causation and care of the dying', *Journal of Law and Medicine*, 1995: 3; 152

Ashby, M., *Medical Journal of Australia*, 1995: 162; 596

——'How we die: A view from palliative care', *QUT Law Review*, 2016: 16; 5

Australian Health Services Research Institute, University of Wollongong Australia, *Palliative Care Outcomes Collaboration*, http://www.pcoc.org.au/

Barbato, M., 'Death is a journey to be undertaken', *Medical Journal of Australia*, 1998: 168; 296

Battin, M.P., 'Legal physician-assisted dying in Oregon and the Netherlands: Evidence concerning the impact on patients in the "vulnerable" groups', *Journal of Medical Ethics*, 2007: 33; 591

Billings, J.A. and S. Block, 'Slow euthanasia', *Journal of Palliative Care*, 1996: 12; 21

Bolt, E. et al., 'Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living?' *Journal of Medical Ethics*, 2015: 41; 592

Bottomley, D. and G. Hanks, ‘Subcutaneous midazolam infusion in palliative care’, *Journal of Pain and Symptom Management*, 1990: 5; 259
Bradshaw, J., ‘Stroke revisited’, *Ockham’s Razor*, ABC Radio National, 12 May 2013
Broom, A., ‘On euthanasia, resistance and redemption: The moralities and politics of a hospice’, *Qualitative Health Research*, 2011: 20; 1
Burke, A. et al., ‘Terminal restlessness: Its management and the role of midazolam’, *Medical Journal of Australia*, 1991: 155; 485
Cassell, E.J., ‘Diagnosing suffering: A perspective’, *Annals of Internal Medicine*, 1999: 131; 531
Charmaz, K., ‘Loss of self: A fundamental form of suffering in the chronically ill’, *Sociology of Health and Illness*, 1983: 5; 168
Chater, S. et al., ‘Sedation for intractable distress in the dying: A survey of experts’, *Palliative Medicine*, 1998: 12; 255
Chochinov, H.M. et al., ‘Burden to others and the terminally ill’, *Journal of Pain and Symptom Management*, 2007: 34; 463
Christakis, N., ‘Too quietly into the night’, *British Medical Journal*, 2008: 337; 326
Clark, D., ‘Palliative care or assisted dying? We just need to start talking more about “the right to die well”’, *The Conversation*, 30 March 2016
Cohen, M. et al., ‘Treatment of intractable dyspnoea—Clinical and ethical issues’, *Cancer Investigation*, 1992: 10; 317
Corner, J., ‘More openness needed in palliative care’, *British Medical Journal*, 1997: 315; 1242
Cousins, M., *The Age*, 12 February 2010
de Sousa, E. and B. Jepson, ‘Midazolam in terminal care’, *Lancet*, 2 July 1988

Doyle, D., ‘Have we looked beyond the physical and psychosocial?’, *Journal of Pain and Symptom Management*, 1992: 7; 302
Doyle, D., foreword in F. Randall and R.S. Downie, *Palliative Care Ethics*, OUP, 1999 (2nd edition)
Emanuel, L., ‘Facing requests for physician-assisted suicide’, *JAMA*, 1998: 280; 643
Enkin, M. et al., ‘Death can be our friend’, *British Medical Journal*, 2011: 343; d8008
Fishbein, D. et al., ‘An approach to dyspnoea in cancer patients’, *Journal of Pain and Symptom Management*, 1989: 4(2); 76
Ganzini, L. ‘The challenge of new legislation on physician-assisted death’, *JAMA Internal Medicine*, 2016: 176; 427
Gawande, A., *Being Mortal*, Metropolitan Books, 2014
Georges, J.-J. et al., ‘Requests to forgo potentially life-prolonging treatment and to hasten death in terminally ill cancer patients: A prospective study’, *Journal of Pain and Symptom Management,* 2006: 31; 100
Hardin, N. and M. Cohen, ‘Unmet needs in the management of neuropathic pain’, *Journal of Pain and Symptom Management*, 2003: 25; S12
Hardy, J., ‘Sedation in terminally ill patients’, *Lancet*, 2000: 356; 1866
Hitchcock, L.S. et al., ‘The experience of chronic nonmalignant pain’, *Journal of Pain and Symptom Management*, vol. 9, No. 5, July 1994: 312–18
Hitchens, C., *Vanity Fair*, June 2011
Hunt, R., ‘Taking responsibility for affecting the time of death’, *Palliative Medicine*, 1999: 13; 439
——‘A critique of the principle of double effect in palliative care’, *Palliative Medicine*, 1998: 6; 214
Hunt, R., ‘Palliative care: The rhetoric–reality gap’, in H. Kuhse (ed.), *Willing to Listen—Wanting to Die*, Penguin Books, 1994

Hunt, R. et al., ‘The incidence of requests for quicker terminal course’, *Palliative Medicine*, 1995: 9; 167
Hutton, N., quoted in *South Australian Voluntary Euthanasia Society Newsletter*, 1 March 2007
Johnson, D.C. et al., ‘Barriers to effective symptom management in hospice’, *Journal of Pain and Symptom Management*, 2005: 29; 69
Kellehear, A., ‘Reason and reasonableness’, Annual General Meeting, Dying With Dignity Victoria, 2000
Klein, M. ‘Voluntary active euthanasia and the doctrine of double effect’, *Health Care Analysis*, 2004: 12; 225
Koeck, C., ‘Imbalance of power between patients and doctors’, *British Medical Journal*, 2014: 349; g7485
Kohlwes, R.J. et al., ‘Physicians’ responses to patients’ requests for physician-assisted suicide’, *Archives of Internal Medicine Journal*, 2001: 161; 657
Komesaroff, P.A. and J.N. Lickiss et al., ‘The euthanasia controversy: Decision-making in extreme cases’, *Medical Journal of Australia*, 1995: 162; 594
Kuhse, H. and P. Singer, ‘Euthanasia: A survey of nurses’ attitudes and practices’, *Australian Nurses Journal*, 1992: 21; 24
Lawton, J., *The Dying Process: Patients’ Experiences of Palliative Care*, Routledge, 2000
Leeder, S., ‘Dying well’, *MJA InSight*, issue 46, 30 November 2015
Librach, L., *Ottawa Sun*, 7 November 2007
Loewy, E., ‘Ethical considerations in executing and implementing advance directives’, *Archives of Internal Medicine Journal*, 2001: 161; 329
Lunney, J. et al., ‘Patterns of functional decay at the end of life’, *JAMA*, 2003: 289; 2387
MacDonald, N. et al., ‘Cachexia–Anorexia–Asthenia’, *Journal of Pain and Symptom Management*, 1995: 10; 151
McGee, E., ‘Can suicide intervention in hospice be ethical’, *Journal of Palliative Care*, 1997: 13; 27

McPherson, T., ‘Without assisted dying our mum died slowly and in pain’, *British Medical Journal*, 2012: 344; 35
Maddocks, I., ‘Divided opinion’, *MJA Insight*, issue 45, 23 November 2015
Maltoni, M. et al., ‘Palliative sedation in end-of-life care and survival’, *Journal of Clinical Oncology*, 2009: 30; 1378
Martin, D., L. Emanuel and P. Singer, ‘The dying process: Patients’ experiences of palliative care’, *Lancet*, 2000: 356; 1672
Masefield, J., *Gallipoli*, S.B. Gundy, 1916
Norwood, F., *The Maintenance of Life*, Carolina Academic Press, 2009
O’Neill, D. ‘We are not alone’, *British Medical Journal*, 2011: 342; 1366
Peruselli, C. et al., ‘Outcome evaluation in a home palliative care service’, *Journal of Pain and Symptom Management*, 1997: 13; 158
Pidgeon, T. et al., ‘A survey of patients’ experience of pain and other symptoms while receiving care from palliative care services’, *BMJ Support Palliative Care*, 5 March 2015
Porter, H., *The Paper Chase*, UQP, 1980
Rabow, M. et al., ‘The role of nurse practitioners in end-of-life care—Reply’, *JAMA*, 2004: 291; 2432
Randall, F. and R.S. Downie, *Philosophy of Palliative Care: Critique and Reconstruction*, OUP, 2006
Reiner, J., *The Man Who Couldn’t Eat*, Gallery Books, 2011
Rich, B., ‘Pathologizing suffering and the pursuit of a peaceful death’, *Cambridge Quarterly Healthcare Ethics*, 2014: 10; 1017
——‘Prognosis terminal: Truth-telling in the context of end-of-life care’, *Cambridge Quarterly Healthcare Ethics*, 2014: 209–19
Robb, P., *Lives*, Black Inc., 2012
Rowett, D. and D. Currow, ‘Pharmacovigilance in palliative care’, *Australian Prescriber*, 2014: 37; 204
Saunders, C., *Lancet*, 2 September 1961

Seale, C. and J. Addington-Hall, ‘Euthanasia (why people want to die earlier)’, *Social Science and Medicine*, 1995: 40; 581
Sheahan, L., ‘Exploring the interface between “physician-assisted death” and palliative care’, *Internal Medicine Journal*, 2016: 46; 443
Sokol, D., ‘What does the law say?’ *British Medical Journal*, 2008: 337; 22
Span, P., ‘Wounded by the language of war’, *New York Times*, 11 April 2014
Starks, H. et al., ‘Why now? Timing and circumstances of hastened deaths’, *Journal of Pain and Symptom Management*, 2005: 30; 215
Stevens, C. and R. Hassan, ‘Nurses and the management of death, dying and euthanasia’, *Medicine and Law*, 1994: 13; 541
Sulmasy, D. and E. Pellegrino, ‘The rule of double effect’, *Archives of Internal Medicine Journal*, 1999: 159; 545
Sulmasy, D., ‘A biopsychosocial-spiritual model for the care of patients at the end of life’, *The Gerontologist*, 2002: 291; 493
Syme, R., *A Good Death*, MUP, 2008
Tolstoy, L., *The Death of Ivan Ilyich*, Vintage Books, 2012, first published 1886
Twycross, R. and I. Lichter, ‘The terminal phase’ in *Oxford Textbook of Palliative Medicine*, 1993, pp. 651–61
Ventafridda, V. et al., ‘Symptom prevalence and control during cancer patients’ last days of life’, *Journal of Palliative Care*, 1990: 6; 7
Walsh, D., *Lancet*, 1993: 342; 350
Zimmermann, C. et al., ‘Effectiveness of specialized palliative care: A systematic review’, *JAMA*, 2008: 299; 1698

INDEX

abdominal pain 60–1, 71–2, 167
abortion 152, 156
Addington-Hall, Julia 87
advance directives 5, 6, 10, 32, 41, 44, 150–1
advanced incurable illnesses
    and assisted dying 117–18, 181
    categorising 62–3
    definition 15, 48
    legal aspects 43, 176–8, 179–80
    and suffering 67
    and suicide 66
    timeframe to death 178
    see also specific illnesses e.g. motor neurone disease (MND)
age 42, 50
aged care institutions 50, 170, 171
agents (medical enduring power of attorney) 15, 78, 170
Ahmedzai, Sam 104
Alfred Hospital, Melbourne 137
Alice 16, 18–19
Alzheimer's disease 50
American Academy of Hospice and Palliative Medicine (AAHPM) 105
anaesthetic coma 89
    see also terminal sedation
Anna 16, 19–20
antidepressant drugs 84
Armstrong, David 138
arthritis 64
Arvay, Joe 160
Ashby, Michael 77, 86, 88, 106, 175
assisted dying

access to 181
and advanced incurable illnesses 117–18, 181
aims 106–7
for babies 158
described 128–30
and disabled people 115–18
and doctors 116–17, 139–40
doses 139, 140
experiences of 148–9
framework 180–1
legal aspects 116–19
and nurses 108–10
opposition to 51, 97, 103, 105, 158
outcomes following legalising 157–8
and palliative care 173–4, 175, 182–3
and palliative care physicians 108
and religion 108
vulnerable people 118–19
see also hastened death; legislation on assisted dying
assisted suicides
legal aspects 31–2, 182
opposed to legislation 101
requests for 96
see also hastened death
Atkinson, Bob 182
Australian and New Zealand Society of Palliative Medicine 81, 100, 103, 150
Australian Catholic Bishops Conference 103
Australian Christian Lobby 103
Australian Commission on Safety and Quality in Health Care 66
Australian Family Association 103
Australian Health Practitioner Regulation Agency (AHPRA) 155
Australian Medical Association (AMA) 81, 110, 150
Australian Nursing and Midwifery Federation (Victorian Branch) (ANMF) 109
Australian Story (ABC program) 33, 155
autonomy
Catholic approach 103
and palliative care 107–8, 173
of patients 28, 44, 79, 103, 104–5, 151, 183

babies 158
back pain 63
Barbato, Michael 142, 169
Battin, MP 118, 119
Baume, Peter 152
Belgium 105, 158–9, 174
Benedict XVI, Pope 101–2
Betty 16, 17

Bill 55–6, 163–6
Bill 52 (Canada) 161
Billings, Andrew 89–90, 94
bioethics 28, 103
Block, Susan 89–90, 94
Bolt, Eva 157, 159
Bonnin, Alastair 100–1
Bottomley, David 92
bowel 59–61
Bradshaw, John 53, 171
brain disease 53
breathlessness 52–3, 70–1, 86, 92
Bron 57–9
Broom, Alex 101–2
Brown, Jerry 159–60, 183
Broyard, Anatole 43–4
burden 23, 120
burden of care 113, 120–3
burial 185
Burke, Alexandra 89

cachexia 71
Cade, David 136
Cade, John 25
California Medical Association 159–60
Canada 160–2, 177
Canadian Bar Association 161
Canadian Medical Association (CMA) 162
Canadian Supreme Court 177
Canberra CityNews 136
Canberra Hospital 136
cancer
    and antidepressant drugs 84
    death rates 49
    end-of-life conversations 35–6, 40–2
    experiences of 1–2, 3, 17, 18, 19, 21, 22, 34, 43–4, 72, 74, 135–7, 155
    Netherlands 34
    and pain management 86
    and palliative care 134–5
    trajectory to death 50
cardiovascular diseases 51–2
carers
    and burden 120–3
    experiences of 4, 54, 58–9
    see also partners
Carolyne 163–6
Carter, Kathleen 160, 177

Carter v Canada (Attorney General) (2015 SCC 5) 160
Cassell, Eric 77, 87, 164
Catholic Church 25, 101–3, 186
Catholic Health Australia 103
Change to die for? 131–2
Charles 166–9
Charles, Stephen 180
Charmaz, Kathy 76–7
Charter of Rights and Freedoms (Canada) 160
Chater, Susan 89, 92
children 158
Chochinov, Harvey 122
choice 104, 131–2
  respect for 20
choking 9, 56
Christakis, Nicholas 119
chronic musculoskeletal conditions 64–5, 66
chronic organ failure
  end-of-life conversations 38, 42–3
  trajectory to death 50
chronic pain
  and cancer 86
  common reasons for 65
  end-of-life conversations 38–9, 43
  experiences of 60–2, 65
  management 65
  spinal 63–4
Clark, David 99, 105, 106–7
Cle 140
Cobb, Luther 160
Cochrane review 84
cognition, loss of 73
Cohen, Martin 51, 70–1
Cohen, Mitchell 86
College of Physicians and Surgeons of New Brunswick 161
College of Physicians and Surgeons of Ontario 161
communication
  loss of 3–4, 56
  open 23, 114
  see also end-of-life conversations
Consent to Medical Treatment and Palliative Care Act 1995 (SA) 42, 177
constipation 12–13, 71–2
control
  loss of 113, 114
  sense of 114–15
control over end of life 28–9, 128, 129, 131–2, 150–1
  benefits of 40–1
  certainty of outcome 19

lack of and suffering 20
loss of 23
value of 24, 26–7
conversations *see* end-of-life conversations 133
Corner, Jessica 93
coroners
reporting deaths to 22–3
reviews 134
counselling 30, 44–5
see also end-of-life conversations
Cousins, Michael 86
Cowie, Lesley 79
Cox, Nigel 64
cremation 186
Crick, Nancy 62, 182
Crimes Act 1958 (Vic) 31, 180
Criminal Code (Canada) 160
Crohn's disease 61–2
Currow, David 83–4

Davies, Nick 16–17
deafness 73
death
attitudes to 79
'bad' 93
good 97, 115, 125, 127, 139, 140, 142, 151, 170
social 75
sudden 127
timeframe to 177–8
trajectories to 50, 66
types of 132
see also dying; end of life; hastened death
death rates 49–50
decision-making
Catholic 103
and children 158
considered 18
and doctors 40, 78, 124
power to patients 28, 44, 75, 129–30
see also end-of-life conversations
dehydration 55, 134
dementia 73
carers 121–2
end-of-life conversations 39, 40, 159
Demos 133
Denton, Andrew 154–5, 157
dependency 87

depressed mood 73
Devlin, Justice 91
diarrhoea 71
digestive system, problems 71
Dignitas 178
dignity 111–15
  loss of 12, 112
disabled people 115–18
do no harm 78–9, 95
Do Not Resuscitate (SBS documentary) 26
Dobron, Rudi 1–15, 77, 134–5
doctor-patient relationships 28, 44, 78, 108
  advanced incurable illnesses 178
  imbalance 78
  lead by patients 127–8
  see also end-of-life conversations
doctors
  and assisted dying 116–17, 139–40
  and best interests of patients 151
  and *Crimes Act 1958* (Vic) 31, 180
  hastened death requests 28, 78
  as 'healers' 48
  and patients autonomy 28, 79, 104, 151, 183
  prosecution of 153, 154
  and right to refuse treatment 133–4
  and suffering 27, 48, 104, 164
  and terminal sedation 89
  trust in 174
  see also palliative care physicians
Donelly, Beau 137–8
Downie, RS 96
Doyle, Derek 82, 102
drinking *see* fluids
drugs
  adverse effects from 83–4, 86
  doses 139, 140
  and palliative care physicians 105
  see also medication
dying
  with dignity 111, 112, 114–15
  at home 138–9
  process 111, 113
  trajectories to death 50, 66
  see also end of life; end-of-life conversations; hastened death; time to die
dying people
  assessment scales for 85
  saying goodbye 21, 187
  see also suffering

Dying With Dignity Victoria (DWDV) 30, 107, 156
dyspnoea *see* breathlessness

Economist Intelligence Unit 171
elderly, frail
  end-of-life conversations 37, 40
  loneliness 75
  trajectory to death 50
  vulnerable 118–19
Emanuel, Linda 28, 89
empathy 68–9
end of life
  definition 66, 95
  medical statements about 27–8
  preferences 131–2
  symptoms at 27, 71–2, 86–7, 89
  see also control over end of life; terminal illnesses
end-of-life conversations
  analysis of contacts 34–43
  cancer 35–6, 40–2
  chronic organ failure 38, 42–3
  chronic pain 38–9, 43
  dementia 39, 40, 159
  doctors providing 44
  elderly, frail 37, 40
  feedback on 23, 31, 34, 40, 59, 145–8, 167–8
  incidence of requests 40
  motor neurone disease (MND) 33, 36
  multiple sclerosis (MS) 36
  need for 18
  neurological disease 36, 42
  numbers of 32–3
  Parkinson’s disease 36
  providing 31, 32–3, 41–2, 44–5, 127–8
  psychological illnesses 39
  in United States 160
  value of 45–6, 178
  when to have 170
Enkin, Murray 79
Erica, Bernard 33, 154, 155
ethics 94, 105, 173
euthanasia
  in Netherlands 34–5
  and nurses 108–9
  opposed to legislation 101
  and palliative care 105–6
  requests complied with 35

requests for 34, 46
slow 21, 89–90
see also assisted dying
existential suffering 13–14, 23, 74–7, 113

Faine, Jon 26
families 121, 125, 128–9, 138–9
experiences of 90, 126, 134, 135–6, 141–5, 147–9, 166–9
see also carers
Fishbein, David 70
fluids
and palliative care 93–4
refusal of 5, 105
right to refuse 5–6
food
refusal of 5, 105
right to refuse 5–6
Frank 24–5
Freddy 141–2
funerals 186, 187

Ganzini, Linda 116
Gawande, Atul 142
George 61–2, 147
Georges, Jean-Jacques 95–6
Gibbs, Louise 18
Go Gentle Australia 157
Godbold, Ray 154
Gold, Michelle 110
A Good Death 15, 16, 17, 29, 32–3, 54
governments 81, 85
Grattan Institute 131, 150, 170
Greta 60–1
Griffith University 121–2
Groningen Protocol 158
Groot, Jack de 84
Guest, Steve 17, 25, 26–7, 33, 41, 152, 153–4

Haller, Katrina 79
hallucinations 7–8
Hanks, Geoffrey 92
Harden, Norman 86
Hardy, Janet 92
Harold 20, 54
Harrison, John 86
Hartland, Colleen 156
Hassan, Riaz 108–9

hastened death
double effect of 93
legal aspects 91
and palliative care 27–8, 172–3
requests for 28, 74, 78, 95–6, 101, 105
and terminal sedation 91–2, 94
see also assisted dying
Hawking, Stephen 57
headaches 8–9, 13
heart 51–2
heart disease 18
Helen 23
Hillman, Ken 133
Hitchens, Christopher 3, 72
Hivon, Veronique 161
hope 114
hopeless illnesses 29, 47
see also advanced incurable illnesses
hospice 96, 99, 101–2
definition 81
Howard 22, 23, 134
Hughes, Mick 182
Hunt, Roger 78, 88, 92, 93, 95
Hutton, Nancy 105

Ilyich, Ivan 125
inclusion body myositis 58
incontinence 8, 12–13, 72
incurable illnesses 47
see also advanced incurable illnesses
independence 23

Jadad, Alejandro 79
Jane 21–2, 23, 134
Jennings, Gavin 156
Jepson, Bridget 89
Jim 23, 147–8
John Paul II, Pope 112
Johnson, Daniel 87
Johnson, Peter 85

Kamisar, Yale 43
Kaposi's sarcoma 139
Keith 21
Kellehear, Allan 106
Ken 18
Key, Steph 156

kidney failure 164
Klein, Martin 95
Koeck, Christian 78, 95
Kohlwes, Jeffrey 96
Kohlwes, RJ 74
Komesaroff, Paul 180
Kourakis, Justice 5–6
Kowhles, RJ 122
Kuhse, Helga 108

Lancee, Alida 156
Lawton, Julia 51, 72, 99
Leeder, Stephen 171
legal aspects
    advanced incurable illnesses 43, 176–8, 179–80
    assisted dying 116–19
    assisted suicides 31–2, 182
    and disabled people 115–16
    hastened death 91
    patient's rights 78
    sanctity of life principle 108
legislation on assisted dying 105–6, 109–10, 152, 156–60, 173–4, 175–6
    Canadian 160–2
    opposition to 101
    support for 183–4
    see also Victorian parliamentary inquiry into end of life choices
Len 18, 41
LeRoy, Rae 52
Librach, Larry 106
Lickiss, Norelle 54, 104–5
Liverpool Care Pathway 99–100
Loewy, Erich 91, 94
loneliness 75
Lorenzini, Albert 154
Lovell, Graham 136
lungs 52
Luther, Martin 107
Lynn, Joanne 50

McCarthy, John 138–9
McDonald, Ian 134
MacDonald, Neil 71
McGee, Ellen 99, 102, 106
McPherson, Ann 135–6
Maddocks, Ian 100, 106, 174
Magnusson, Roger 27
malpractice 118

Maltoni, Marco 91
Margaret 16, 17, 20
Martin, Chief Justice 6, 55
Martin, Douglas 28
Mary 166–9
Maynard, Brittany 160
meaning, loss of 75
Medew, Julia 10, 11, 14
medical agents *see* agents (medical enduring power of attorney)
Medical Board of Australia 155
medical enduring power of attorney (MEPA) 5, 6, 32, 41, 44, 118
Medical Treatment Act 1988 (Vic) 5, 91, 118
medication provision 24, 41, 128, 129, 182
    see also Nembutal
Melbourne Catholic Archdiocese 103
Melbourne Seven 17
Menhennitt, Justice 152
Michael, Natasha 77–8
Mills, Janet 51
Montana (US) 159
morality 103
morphine 2, 86, 135, 139
motor neurone disease (MND) 56–7, 138–9
    bulbar 3, 56
    end-of-life conversations 33, 36
    experiences of 3, 20, 23, 142–8
    Netherlands 34–5
mouth care 5, 55, 134
multiple sclerosis (MS)
    end-of-life conversations 36
    experiences of 18–19, 21–2, 137–8
musculoskeletal system 64–5

nausea 71
Nembutal
    provision of 26, 33, 129, 153–4, 155, 167
    taking of 129–30, 148, 168–9
nervous system 53
Netherlands 34–5, 141–2, 157, 158–9, 174
neurological diseases, end-of-life conversations 36, 42
Nietzsche, Friedrich 165–6
Nitschke, Philip 62
Norwood, Frances 45–6, 75, 87
Not Dead Yet 115
nurses 81, 108–10
    see also palliative care professionals
nursing homes 50, 170, 171

Ockham's Razor (ABC radio) 53
O'Connor, Justice Sandra Day 91–2
Office of Public Prosecutions 153
Olle, John 132
O'Neill, Desmond 120
Oregon (US) 105, 142, 157, 174–5
organ failure *see* chronic organ failure
Osler, Sir William 104

P (patient) 139
pain
  abdominal 60–1, 71–2, 167
  back 63
  personal component 69–70
  somatic 62
  total pain syndrome 76, 87
  see also chronic pain
pain management
  and cancer pain 86
  and chronic pain 65
  and headaches 8–9, 13
  limits of 86
palliation, definition 48
palliative care
  aims 106–7
  and assisted dying 173–4, 175, 182–3
  and autonomy 107–8, 173
  benefits of 84–5
  and cancer 134–5
  and Catholic Church 101–3
  claims of 98–9
  definition 81
  early history 48–9, 50–1, 80–1
  and euthanasia 105–6
  experiences of 6–15
  and fluids 93–4
  future of 171–4
  and governments 81, 85
  and hastened death 27–8, 172–3
  and hope 114
  model of care 99–100, 108, 124–5
  reformation 107
  and religion 96–8, 100, 101–4, 107
  rhetoric and reality gap 82, 107
  and sanctity of life 173
  and suffering 27–8, 81–2, 88
  and terminal sedation 90–1

understanding of 107–8
values 107
see also specific illnesses e.g. motor neurone disease (MND)
Palliative Care Australia 27, 88, 95, 101, 103, 150, 172
Palliative Care Outcomes Collaboration (PCOC) 87
palliative care patients
and burden 120–3
concerns of 87–8
hastened death requests 28, 74, 95–6, 101, 105
and palliative care professionals 124–5
symptoms at end of life 27, 71–2, 86–7, 89
vulnerability 119
palliative care physicians 81
and assisted dying 108
drug administration 105
hastened death requests 74, 95, 105
and legislation 110
see also doctors
palliative care professionals 14, 81, 183
opposed to assisted dying 97, 103, 105
and palliative care patients 124–5
sedation unease 92
and voluntary euthanasia 106, 125–6
palliative care research 83–5
palliative care services
integration of 82
standard of 171
see also hospice
Palliative Care Victoria (PCV) 101, 107
Pamela 21
Parkinson's disease, end-of-life conversations 36
partners, experiences of 10–11, 53–4, 136–7, 146–7, 163–6
pastoral care workers 7
patient-doctor relationships 127–8
patients
autonomy of 28, 44, 79, 104, 151, 183
and consent 90
rights of 78, 119
as a term 164
see also palliative care patients
Paynter, John 136–7
Pell, George 102
Pellegrino, Edmund 93
pentobarbital *see* Nembutal
percutaneous endoscopic gastrostomy (PEG) 3, 71
Peruselli, Carlo 84
Petitclerc, Chantal 117
physical suffering 3, 69–73

Physician Assisted Dying Bill of 2008 (Vic) 152
Pidgeon, Tanya 87–8
Player, Ron 74
Porter, Hal 69–70
Pos, Margareta 126
psychiatric assessments 61
psychiatric illnesses 24–5, 159
psychological illnesses, end-of-life conversations 39
psychological suffering 13, 55, 72–4, 113

Q&A (ABC program) 33, 155
quadriplegia 54–5, 163
    end-of-life conversations 36

R v Adams (UK) 91
Rabow, Michael 121
Randall, Fiona 96–8
Reformation 107
refractory symptoms 9, 88, 94, 105, 172
    and terminal sedation 90–1
Reiner, Jon 4
religion
    and assisted dying 108
    and palliative care 96–8, 100, 101–4, 107
rheumatoid arthritis 64
Rich, Ben 74, 95, 99
right to refuse to eat and drink 5–6
right to refuse treatment 5, 56, 78, 133–4, 164–5
Rights of the Terminally Ill Act 1995 (NT) 51
Robb, Peter 138–9
Rossiter, Christian 55
Rowett, Debra 83–4
Royal Australasian College of Physicians (RACP) 81, 82

sanctity of life principle 103–4, 108, 173
Saul, Peter 133
Saunders, Dame Cicely 50–1, 76, 81, 82, 87, 114–15
scales, assessment 85
Schiavo, Terri 112
Seale, Clive 87
sedation 9–10, 88, 92
    see also terminal sedation
self, loss of 76–7
Shakespeare, William 112
Sheahan, Linda 95
Shenton, Lynda 145–6
Short, Peter 154

sight, loss of 73
Sing, Margaret 156
Singer, Peter 28, 108
skin 51
slow euthanasia 21, 89–90
Smith, Justice Lynn 119, 160
Smith, Richard 79
social circumstances 42
social death 75, 87
social interaction 52–62
social workers 81
Sokol, Daniel 151
somatic pain 62
Sousa, Emile de 89
South Australian Voluntary Euthanasia Society 156
Span, Paula 52
speech, loss of 3, 72
spinal cord
    acute injuries 54–6, 63–4
    see also back pain
spirituality 102
Starks, Helene 174–5
starvation 134
Stevens, Christine 108–9
strokes 53, 134
    experiences of 20, 53–4
suffering
    and advanced incurable illnesses 67
    assisted dying access 181
    Christ's 68
    and do no harm 78–9
    and doctors 27, 48, 104, 164
    doctor's role 104
    and dying with dignity 114
    escalates 27
    hasten death to relieve 18
    loss of self 76–7
    measuring 21, 41, 85–6
    not confind to dying 19
    not just physical pain 20
    and palliative care 27–8, 81–2, 88, 106
    types of 69
    will only end with death 17, 27
suicides
    and health problems 66, 132–3
    see also assisted suicides
Sulmasy, Daniel 85, 93
Sunday Age 31

Supreme Court of New South Wales 173
Susan 24, 41
swallowing, difficulty 5
Switzerland 157–8
Syme, Rodney
  as counsellor 30–1
  and Medical Board of Australia 155
  and Steve Guest 152, 153–4
sympathy 68
symptoms at end of life 27, 71–2, 86–7, 89
  see also refractory symptoms

Tallis, Raymond 93
Taylor, Gloria 160
terminal illnesses 15
  definition 177
  terminal phase 41–2, 87, 177
terminal sedation
  described 20–1, 88, 94
  early history 89
  and ethics 94
  and hastened death 91–2, 94
  increase in 158
  and palliative care 90–1
  provision of 21
  reporting deaths to coroner 22–3
  as slow euthanasia 21, 89–90
  unconsciousness 22
  unease 92
  use of 89, 90
Termination of Life on Request and Assisted Suicide Act 2002 (Netherlands) 141
time to die 45, 75, 79, 151, 178–9
total pain syndrome 76, 87
treatment
  refusal of life-sustaining 105
  requests for 78
  right to refuse 5, 56, 78, 133–4, 164–5
  withdrawal of 133
Trudeau, Justin 161
Twycross, Robert 91

'unbounded body' 51, 72, 135
unconsciousness 22
United States 159–60
  see also Oregon (US)

values 107

Ventafridda, Vittorio 81–2, 89
Vermont (US) 159
Victorian Law Reform Commission (VLRC) 156
Victorian parliamentary inquiry into end of life choices 156, 175–6, 179, 180–2
  evidence to 66, 88, 110
  safeguards 181–2
  submissions to 101, 107, 109, 110, 137
Virgona, Anthony 137–8
Vlessing, Marc 141
voice, loss of 72
voluntary euthanasia
  described 125–7
  experiences of 141–2
  and palliative care professionals 106, 125–6
Voluntary Euthanasia Society of Victoria *see* Dying With Dignity Victoria (DWDV)
vomiting 71
vulnerable people 115–20, 180

Walsh, Declan 92
Washington (US) 157, 159
Wasim 24
wasting disease 71
Wheeler Centre 154
Winterson, Jeanette 32

Zimmermann, Camilla 84